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ABSTRACT

The handbook provides an overview of residential services for mentally retarded persons. An introductory section defines the term and cites major problems associated with the service. Philosophy and 13 basic principles are covered in the second chapter. Among the goals cited in Chapter 3 are learning to learn, skills training, and opportunities to meet hierarchical needs. Burnout is one topic considered in a section on staff factors, while another on environmental influences examines the concept of least restrictive alternative. Program design aspects touch on social skills, mobility, decision making and autonomy, and self care. Suggestions are made for developing and monitoring individual program plans. A final chapter addresses accountability and its implications for advocacy and monitoring. (CL)

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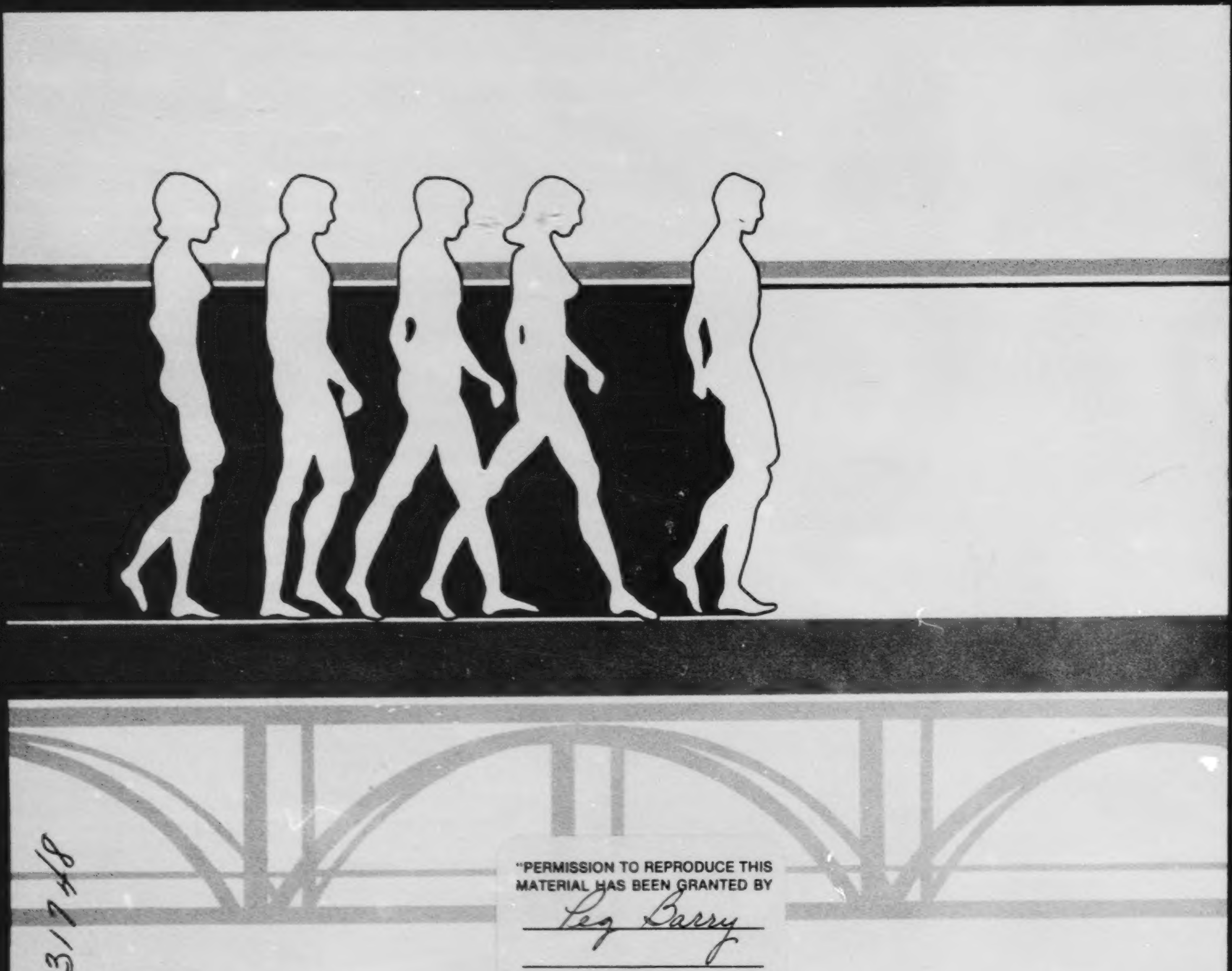
Bridges

A RATIONALE FOR RESIDENTIAL SERVICES

VOLUME 1



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BRIDGES

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INTRODUCTION

1

Bridges —

Most of us take them for granted. They serve as a link between one point and another along a path we are traveling to reach a destination.

They make it possible for us to span gullies that would be too deep or wide for us to easily cross otherwise. They smooth our way.

Some bridges are wondrous marvels of engineering that are crossed by millions. Others are as simple as a plank laid down between the boat and the shore.

But, there are other kinds of bridges — less tangible and located not on a map, but in the geography of our minds.

One example of this tvpe of bridge is the role that the right kind of residential service can play in the life of a mentally retarded person as he struggles to span the distance between life isolated from the community to life fully experienced *within* the community.

The main goal of this publication (Volume One) is to clearly define for the reader the meaning of the term "residential services for mentally retarded persons" and to illustrate the purposes such services can fill in their lives.

Bridges Volume Two: A Continuum of Residential Services deals in more detail with the variety of current service models and how they work.

If parents and other advocacy groups are to make honest and appropriate decisions about services for the community's mentally retarded children and adults, they must basically understand what happens when a mentally retarded person enters some type of residential program.

Residential Services and Identified Problems

Let us begin with a basic definition of the term "residential services" as stated in the ARC's national position statements on residential services: "The term 'residential services' is used to describe some type of living condition, other than the individual's natural home."

"A residential service should:

- Provide a home environment with supervision and guidance as needed;
- Afford living experiences appropriate to the age, functioning level and learning needs of the individual;
- Provide access to necessary supportive, habilitative and rehabilitative programs based on a developmental model of programming; and
- Provide access to the mainstream of community life."

Discussion groups of parents and professionals at the ARC's 1977 national convention identified ten major problems associated with such residential services, and these problems served as the stimuli for preparing these two publications. The problems are not listed in priority order although some are obviously more critical than others.

- There has been rapid expansion of residential programs in many different types of settings without an adequate understanding of what those programs are supposed to accomplish.
- Program development is often stymied by lack of knowledge about current approaches and technology to implement programs.
- Staff members are frequently unprepared to design and carry out individualized programs and there are few opportunities (or little encouragement) to improve their knowledge and skills in the areas of residential programming.
- Lack of understanding about human development frequently results in the imposition of a single approach to all aspects of program design (i.e., a medical treatment approach, psychotherapeutic counseling, routinized behavior modification, psychoeducational approaches, etc.). Since the purpose of programs is to prepare mentally retarded persons for functioning in society, program strategies which do not honor and encourage decision making are at cross purposes with program goals.

- Mentally retarded persons are often not allowed to help plan their own individual programs. They are not always given sufficient or even legitimate opportunities for expressing personal interests, goals, concerns and reactions to programs which have been imposed by staff.

- Advocates often lack an understanding of the practical application of basic program principles and are, therefore, unable to realistically monitor services.

- Poor understanding by parents of the mechanisms to assure the safety and security of their offspring in a small community-based residential program results in unnecessary anxiety for everyone involved.

- Lack of appropriate and consistent education for mentally retarded individuals regarding human sexuality results in the potential for inappropriate behaviors on their part which may limit their opportunities to continue in community programs.

- Lack of adequate comprehensive state development disabilities service planning, as well as resistance to interagency cooperation, results in confusion about the expected roles of public and private agencies in supporting the community-based residential facility.

- Unless communities are willing to provide and support the opportunities and services required by retarded persons, community-based residential facilities cannot survive.

- Neighborhood ignorance about mental retardation and the purpose of community services generate resistance to a group living program and may cause insulting remarks or other inappropriate behaviors to be directed toward the home's residents. This can particularly interfere with, or destructively influence, the learning of successful social skills.

These problems may lead to a variety of inconsistent and sometimes distorted assumptions by all concerned about what a residential program is and what it should accomplish. Therefore, in this book, we will attempt to clarify the essential elements and purposes of residential services.

For many years we have grappled with the basic issue of how to best serve mentally retarded people. Some have even questioned whether or not mentally retarded individuals really deserve to have any services in the first place, or whether they should just be treated kindly and given the basic necessities of life. On the other hand, if mentally retarded individuals are really human, rather than some sort of sub-human mutations, then they are automatically full-fledged citizens, and as such, enjoy the full range of rights, privileges and protections guaranteed by our Constitution. The United States' justice system, speaking through our courts of law, has resolved this question. Mental retardation, *per se*, does not automatically alter one's constitutional rights.

PHILOSOPHY & BASIC PRINCIPLES

2

Why talk about philosophy? What has philosophy to do with the practical and realistic operation of good residential services?

The reason we need to talk about philosophy is that too few people have a firm idea about what they should really expect from residential services or what they should expect of **most** services for mentally retarded individuals, or, for that matter, from those mentally retarded individuals themselves! Some professionals and all too many parents genuinely believe that mentally retarded people have little, if any, potential for contributing to the general society. For a variety of different reasons these people believe that, while some mildly retarded individuals can survive in our competitive world, those who are more severely handicapped can survive only in highly protected and segregated situations.

Even those of us who "theoretically" agree that mentally retarded individuals have the right to live in normal community surroundings may still basically feel uncomfortable around them and hold a fundamentally hopeless attitude about their condition. These attitudes will then spill over into the programs we design to help them. And, if the services we develop hold low expectations for retarded individuals, then they will remain infantile and essentially helpless because that is how we expect them to be.

In spite of the surface endorsement of a developmental and normalized approach to services for retarded people, many individuals are still dominated by negative beliefs and attitudes.

IN SEARCH OF A GOAL

All the creatures of the forest took part in a search for the North Pole. There were Christopher Robin, Rabbit, Pooh, Piglet, Kanga, Roo, Owl, Eeyor, and "at the end in a long line," all Rabbit's friends-and-relations.

Anyone who has read **Winnie the Pooh** knows what a variety of personalities this includes: Christopher Robin, the leader who everyone wanted to impress; Rabbit, the organizer, who felt he was smarter than everyone else; Pooh, needing praise, willing to do whatever he was told; Piglet, unsure of himself but trying to cover this by making important noises at the proper time; Kanga, who took part but really cared only about Roo; Roo, always in trouble, distracting the others; Owl, intelligent, disdainful and always anxious to display his knowledge to the others who aren't interested; Eeyor, the eternal cynic, never satisfied, always complaining; and all Rabbit's friends-and-relations, the followers who no one knows too much about.

The thing about Milne's characters is that they are so much like the people we know.

Everyone wanted to help find the North Pole. It was a very important adventure. There were just two big problems — no one could remember, if he ever knew, what they were looking for and didn't want to let anyone else know of his ignorance; and each individual had his own needs which, in reality, were more important to him than the needs of the group. Consequently, the search for the North Pole was a very confused effort. Once the sought-after prize was found, it was only recognizable because Christopher Robin said they had found the North Pole, and that was that.

Perhaps the quest by disabled people for the top of the world is paralleled to the search for the North Pole by the characters of A.A. Milne. Is anyone sure any more what we are striving for, or is it only that it seems such an important thing? Are the needs of one group more important than the needs of the individual? Who will make the final decision that, indeed, now we have found the North Pole, and we can all go home and rest from our efforts?

In another **Winnie the Pooh** story, Pooh ate too much when visiting Rabbit and got stuck in the doorway. Everyone was deciding whether they should try to push Pooh back into the hole or try to push him out of it. Rabbit voted to push him out, because, as he explained it, "having got so far, it seems a pity to waste it."

Maybe we have gotten stuck momentarily, unsure of which way to go. Maybe it is time to reassess our goals, pause and plan for the future before racing rapidly to a goal we are no longer sure of. The needs of so many are involved, and it is possible that the strong will overpower the weak in determining the goal. If we are not exactly sure of the goal, we are sure that the need is to help the less strong, not to overpower them.

We have a long way to go. We may not reach the top of the world for a long time. But we should all be able to recognize it when we get there. More than that, many have now joined in the search and having come so far, as Rabbit says, it seems a pity to waste it.

Dianne Lattin
Performance, September 1976
The President's Committee on
Employment of the Handicapped,
Washington, D.C.

Defining Goals

One of the chief reasons for confusion and disagreement about the way in which residential services are provided relates directly to a widespread confusion about our goals for these services.

As parents and professionals, and just "interested parties," we haven't been altogether successful in clearly defining goals even for our non-retarded children. Parents generally want their children to be healthy, happy and economically secure. Beyond that, parents hope for a good relationship with their children but often tend to think about development as something generally beyond their influence and understanding — more closely associated with fate than with parental management. We **expect** the non-retarded child to become increasingly independent and socially adaptive. The mechanisms by which this process occurs are given little attention by many parents and are generally left to society's schooling system.

With the retarded child, however, child-rearing practices, which are usually learned from our own upbringing, are frequently inadequate. Parents of the retarded child find themselves ill-equipped to orchestrate the development of the "different" child, and frustration leads them to seek help outside the family. The help they need isn't always available, and all too often the service they do receive isn't all that helpful in the long-run.

Faced with these frustrations, parents expect professionals to guide them in making the proper decision about their child's development. It comes as a surprise to most families that professionals often seem equally frustrated and confused about what should be done. The advice generated by professionals ranges from one extreme to the other. One expert may urge immediate institutionalization, while another equally recognized expert admonishes the parents to keep the child at home and treat him "normally" — whatever that means.

Since none of us wants to be a "bad" parent or professional, we usually find ourselves emotionally shredded in this parent-professional give-and-take. It is not a process which is beneficial to either the parent or the child, or, for that matter, the professional.

Having a clearly defined philosophy, based on the best scientific understanding available, can resolve much of our confusion about the most appropriate service approach for our mentally retarded sons, daughters and friends.

Every workable and useful philosophy is based on a set of principles or fundamental assumptions about the nature of mankind, the goals of our society and the cultural influences which shape the way we think about our status as human beings.

These basic principles serve to guide us in making decisions about virtually every aspect of our lives. Basic principles are different from rules or recipes. Recipes work only if the ingredients are always the same. Sets of complex rules rarely work since people tend to forget, overlook or misinterpret the rules in their day-to-day decision making. Rules are too frequently seen only as a challenge to be avoided, gotten around or revised.

To illustrate how basic assumptions influence our behaviors, we learn very early that heaters and stoves are hot and will burn us if we touch them. This understanding about the nature of heat is incorporated in a principle or assumption about stoves, and we make automatic decisions to avoid touching hot surfaces. Such an assumption is applied to stoves in general so that we automatically hesitate to touch those surfaces even when they are not hot. We have been conditioned to think a certain way about potentially hot surfaces, and our decisions are strongly influenced by that assumption.

All of our mental processes for making decisions or assessing situations are based on a collection of assumptions or beliefs which are organized into working principles. These fundamental principles govern our day-to-day and moment-to-moment behavior — the decisions we make about how we will behave under various circumstances. Therefore, making decisions about specific services will be strongly influenced by our fundamental assumptions about the nature of mental retardation as well as our basic understanding of human services in general.

Principles for the Service System

Now let us discuss the part played by the ARC in its 30-year history of striving to improve services for mentally retarded persons.

Membership of the Association for Retarded Citizens is made up of an unusually broad sample of the U.S. population. The ARC members are people who have a wide variety of reasons to find themselves functioning in the role of an advocate.

- Some are faced with unexpected responsibilities to a family member who is handicapped by mental retardation.
- Some find themselves responding socially to the recognition that friends and fellow citizens are seriously jeopardized by the handicap of mental retardation.
- Some have vocational interests which lead them into human service professions where they accept a professional responsibility to advocate for the welfare of mentally retarded individuals.
- Some are themselves mentally retarded and are either guided into their interaction with the Association or recognize their own need for an organization which serves as an advocacy voice on their behalf and provides greater social opportunities for them.

An association, composed as broadly as the ARC, tends to be deliberate in its actions, speaking frankly to the problems and issues revolving around the health, education and welfare of mentally retarded persons throughout the nation. Those deliberations have resulted in official position statements about fundamental principles. These principles are supported by scientific data, social responsibility, legal findings and a sense of justice. They serve as guides and standards in the process of designing, improving, revising and expanding the provision of services to aid mentally retarded individuals directly while, at the same time, preventing other children from becoming mentally retarded. When issues involved in making decisions are distilled down to their basic essence, it becomes easier to respond in a precise and logical manner rather than in an intensely emotional way. Emotions are rarely dispelled in an understanding of basic principles; rather they become constructively focused toward finding solutions and remedies for social or professional problems. Principles allow us to think about an issue with the perspective of common judgment and without confusion from personal prejudice or irrelevant side issues.

The following principles, which underlie the ARC's national position statements on residential services, are capsulized here in an effort to give the reader a broad base of understanding to utilize in thinking about residential services for mentally retarded individuals.

PRINCIPLE one

Retarded children and adults are guaranteed the same constitutional rights as other children and adults and may not be deprived of life, liberty, or property, without due process of law; nor shall they be denied equal protection granted by the laws.

The courts have defined liberty to denote a number of different things, among which is "to acquire useful knowledge," and generally "to enjoy those privileges long recognized at common law as essential to the orderly pursuit of happiness by free men" (Meyer v. Nebraska, 1923).

The first principle recognizes our citizenship guarantee to constitutional rights. All human service systems must be compatible with the nation's cultural value system and legal guarantees.

The courts have recently clarified many of those legal rights issues associated with services for mentally retarded and other developmentally disabled citizens. It is safe to work from an assumption that the mentally retarded individual enjoys all of the same privileges of citizenship enjoyed by anyone else. It is only through the legal process that citizenship rights can be suspended, and even then the court should review the case periodically to assure that the individual's rights are restored at the earliest possible time.

It has been noted that the Constitution guarantees the right to vote, to make contracts and to enjoy the freedom of thought so closely associated with the American form of government. However, the Constitution does not guarantee that we **will** vote wisely or that we **will** make good contracts. If, for example, we were required to make good contracts, the nation's marriage and divorce rates would be considerably different.

PRINCIPLE two

Residential facilities of all varieties are particularly vulnerable to conditions or situations which can impair the quality of life for the residents they serve. Facilities become dehumanizing when they become developmentally counterproductive by violating the dignity of the resident and limiting his opportunity to gain "useful knowledge."

The idea of an environment being "developmentally counterproductive" is a crucially important concept in raising our expectations for what a residential service should be. A situation can be considered developmentally counterproductive when it teaches the retarded individual to distrust people, to be dishonest, to be passive and dull or to be socially incompetent. For example, if a mentally retarded person is allowed little power in his own life by others and is given minimal information about actions affecting daily existence; if the mentally retarded person is given false expectations which are rarely met and is not trusted and respected, or is expected to be incompetent, that person is being taught to be distrustful, dishonest and incompetent.

Situations or conditions which interfere with the individual's opportunity to learn are also considered developmentally counterproductive. Situations which interfere with learning can occur in several areas of human activity. For example, if the mentally retarded individual is given no opportunities to practice communicating his ideas, interests or observations then he is effectively being taught **not** to be successful. There are many techniques to assist even the most severely handicapped person to learn to communicate with other people. Some of these approaches will be examined later in this publication.

In addition, if the place where the mentally retarded person lives is crowded, uncomfortable or unsanitary, that environment will interfere with appropriate development and, therefore, becomes counterproductive to the individual's continued mental and physical growth.

It is fairly easy to examine this question of developmentally counterproductive situations and conditions by making a brutally honest assessment of whether a situation encourages new skills or interferes with the learning and practice of personal and social survival.

PRINCIPLE three

Mentally retarded people have a right to appropriate educational and social opportunities which will promote their personal development.

Social expectations are reflected in the priorities given to any particular service. We know from history that so long as the general public held the view that mental retardation was a hopeless situation, no priority was given to providing educational opportunities to this devalued population. However, as the public became better educated and as professionals came to understand that the mentally retarded individual can benefit from proper educational programs no matter what his age or severity of handicap might be, more opportunities were made available within the public school system.

The U.S. Constitution does not expressly state that education is a fundamental constitutional right. Federal courts, however, have ruled in favor of a right to an appropriate education relying upon the "due process" and "equal protection" provision of the U.S. Constitution as support for that conclusion. In the now famous federal court case of **Pennsylvania Association for Retarded Children v. the Commonwealth of Pennsylvania** (1971) the plaintiffs effectively argued that all children can be educated in one fashion or another and that if the state chooses to provide free public education to any of its children it must provide that service to **all** its children. On the basis of research data and the testimony of expert witnesses, the court noted that "the mentally retarded person can benefit at any point in his life and development from a program of education."

In a separate case, that of **Mills v. Board of Education of District of Columbia** (1971), the court based its decision on the due process and equal protection clauses of the Constitution and ruled that no child could be excluded from a regular school assignment unless adequate alternative educational services suited to the child's needs were provided. The child was also to be accorded a constitutionally adequate prior hearing and periodic review of the education program.

These two famous cases set the stage for federal legislation. In enacting Public Law 94-142, the Education for All Handicapped Children Act of 1975, Congress recognized the impact of the "right to education" litigation which was occurring.

Congress maintained that education remained a state responsibility. However, under the Act, Congress also recognized the responsibility of the Federal Government to provide financial assistance to states to assist in the education of handicapped children. The state's educational policy must be consistent with the stated purpose of the Act:

> ". . . to assure that all handicapped children have available to them within the time period specified in the Act, free appropriate public education which emphasizes special education and related services designed to meet their unique needs, to assure that the rights of handicapped children and their parents or guardians are protected, to assist states and localities to provide for the education of all handicapped children, and to assess and assure the effectiveness of efforts to educate handicapped children."

It should be noted that this third principle is not limited only to public educational opportunities for children but applies also to continuing educational opportunities for adults.

PRINCIPLE four

While the learning needs of both retarded and nonretarded persons are continuous throughout their lifetimes, the retarded individual usually has a more intense need for structured learning situations. By the very nature of their handicap, mentally retarded persons require increased or specialized opportunities to learn new skills.

The fourth principle represents a key concept of program expectations. During the past decade, the general opinion has become that custodial (maintenance) programs are an inadequate response to the problems of mental retardation. Likewise, the federal courts have recognized the inappropriateness of purely custodial approaches and have mandated active habilitation programs in the "right to treatment" cases brought before them. It is fair, then, to say that if an individual needs to be admitted to a supervised residential setting, that person also needs an active program designed to teach new skills and to provide those learning opportunities which result in greater independence.

For a range of reasons many people find the concept of "continuous development" or "ongoing studenthood" uncomfortable. There is, of course, the understandable tendency for all of us to equate being a student with our own formal classroom experiences in public schools and colleges. The student role in these settings is naturally associated with complicated books, homework and, worst of all, tests and quizzes. Because of this personal bias about the role of a student, there are those who insist that we should not have to be students after reaching adulthood and, presumably, a state of autonomy.

In reality, however, learning is continuous, and as adults we continue to learn new skills, new ideas and new ways of thinking. Learning, and the student role, is not restricted to highly structured training or classroom situations.

Centuries of observation have led to what may be a basic human axiom — "when learning stops, regression and deterioration begin." For those of us with some kind of handicap, the need for continuous learning becomes even more apparent. To deny our role as students is foolish at best and dangerously arrogant at worst.

A residential program should be a secure place in which to learn new skills, and staff members should think of the program's residents as learner — as **students** in the process of living.

PRINCIPLE five

The retarded individual and the family or guardian should participate in planning for residential placement and/or program participation.

Most everyone agrees that the retarded individual's opinions and interests should be solicited. Often, however, there is a sort of short-circuit in our logic when we think about the retarded person's active participation in setting goals and making decisions. There is an understandable tendency to assume that the person is unable to make appropriate decisions because he is mentally retarded. We forget that not all decisions involve major complex issues. We learn to make good decisioins by practicing. If there are opportunities to decide between alternatives (goals setting), the individual learns to make better decisions and thereby becomes a bit more independent.

As in an interaction with any student, the teacher begins teaching at that point where the student is currently functioning. That is, the teacher must use skills, words and ideas the student already understands to teach **new** words, ideas and skills. In the same way, decision making opportunities must be appropriately simple or difficult, depending upon the capabilities of the student at that time. For example, if the individual wants a toy, there is an opportunity to practice decision making by offering two toys and forcing a choice between them. At bath-time the decisions can be as simple as soliciting a choice of which ear to wash first. This may not seem like a very complicated decision, but it is a start. More complicated ones can come later.

To survive in this or any society, the individual must learn to solve problems about day-to-day events and situations. By the very nature of their disability, mentally retarded persons are slow to learn and remember the associations between those facts and moral values which are called into play when solving problems and making decisions. Therefore, to be successful, any program must provide frequent and consistent opportunities to practice problem solving skills.

Through an expanding electronics technology, there are now dozens of new devices which permit or aid active communications with even the most profoundly handicapped child or adult so that they, too, can participate in making choices in their daily lives.

Finally, we should note that involving the mentally retarded person and his family or guardian in planning for program options has value beyond the surface issue of simple fairness. When everyone understands and accepts the specific goals of a program, the chances for success in reaching those goals are dramatically increased.

PRINCIPLE six

Retarded children and adults should be helped to live as normal a life as possible. The structuring of daily routines, the life-style and the nature of the physical environment should be as nearly like the mainstream of society as possible.

One reason we are concerned about the lifestyle of mentally retarded individuals is because the lifestyle we all lead controls the **things** we learn and the **way** we learn to think. The personal and social routines of life, the values, attitudes and skills associated with a particular culture, or subculture, are learned by growing up and living in that culture. When people move from one culture to another, they often experience rejection by those in their new home because they do not yet understand the etiquette of this different lifestyle.

The individual who is mentally retarded often shares in a kind of cultural rejection because he has failed to learn those social skills that make him acceptable as a member of the society. It is important, therefore, for the child or adult who has difficulty in learning to have regular, consistent and practical experiences in learning social skills. The best way to learn how to live in a community is **to live there.**

A residential program must provide the experience of normal lifestyles as an essential part of the service and also the consistent opportunity to practice the necessary skills in normal situations.

PRINCIPLE seven

Each individual, no matter how severely handicapped, should be approached with the positive expectation that there is potential for progress.

Over the past several years a wide range of research studies have contributed a mass of compelling evidence to illustrate the truth of this seventh principle. There is no justification for assigning any child or adult to a category of hopelessness.

There are still those programs in this country which label certain individuals as having progressed as far as they can be expected to go and assign them to custodial programs. Such expectations are in conflict with both our scientific knowledge and our citizenship guarantees.

PRINCIPLE eight

The basic goal of programming for retarded persons consists of maximizing the individual's personal, social and vocational development, and as such is identical with the goal of educating and socializing all other citizens. The adequacy of programs, as well as of physical and psychological environments, can be evaluated in terms of the degree to which they fulfill this goal.

At an earlier time one of the most often noted and socially sanctioned goals for the institutionalized individual was his rapid adjustment to institutional life. Sub-goals included obedience to irrelevant rules and regulations, acceptance of institutional routines, compliance with the moral code of attendants and relinquishing strong emotional ties to a family. Such goals are now recognized as inappropriate and intolerable in light of our current knowledge.

Individuals in any residential program should be constantly challenged to learn new skills and to exert greater control over their own behaviors. Whatever skill the individual has can always be used to learn another slightly more complex task requiring slightly more controlled mental activity. The same logic applies when considering all developmental tasks, including social and vocational skills.

Assessment and evaluation of a particular residential service are necessarily based on whether or not the students of that service continue to make daily gains in their individual growth and development. In order to meet this rigorous evaluative criterion, service providers must operate their program in such a way as to enjoy everything we know about influences upon human development. Such a requirement necessarily includes the quality of human interactions within an environment and whether or not those interactions help in learning new skills.

PRINCIPLE nine

Specific program objectives must be tailored to meet the needs of each individual and will vary for different degrees of impairment. The best approach, in view of current limitations of knowledge, is to assume that most retarded persons have the potential for greater mental, physical and social development and for eventually leading an independent life style. This approach must dominate program planning until the individual's response to appropriate programs clearly reveals his or her inability to attain this goal.

The ninth principle is drawn from a knowledge that what actually happens in a situation most often reflects the expectations held by the people involved. That is, people generally achieve no more than what they are expected to achieve or what they, themselves, expect to achieve. If little is expected, little is accomplished, and this concept is termed a "self-fulfilling prophecy."

The rich but stormy history of mental retardation services clearly reveals the truth of this principle. The extremely limited expectations commonly held about the "potential" of retarded children were demonstrated in a repetition of program failures within institutions throughout the world. Programs were not designed to capitalize on whatever skills the individual might have because it was assumed that the mentally retarded person either could not learn or did not need to learn. It was a hopeless situation.

As professionals in the field came to realize the harmful impact of having these low expectations, a flurry of fresh research began to reveal more positive information about the disability called "mental retardation." One of the many benefits derived from our increased understanding is the concept of an "individually prepared program plan." The program plan must be based on a careful assessment of the individual's current skills and limitations. In other words, the plan should be like a map — showing the location of a particular client, a clear idea of where to go from that point and a sequence of moves to get there. The program plan is a statement of expectations for individual development and can be changed as the individual progresses.

PRINCIPLE ten

All programs for retarded persons must meet the three basic criteria of the developmental model:

1. Contribute to increasing the individual's ability to control the environment.
2. Contribute to increasing the complexity of the individual's behavior; and
3. Contribute to maximizing those qualities which have been designated as "normal" or human.

Having noted the importance of an individual program plan, we must now ask, "How do we know it's a good plan?"

Knowing where we want to be is often easier than knowing how to get there. There are, however, some criteria or "guide posts" to help in constructing and evaluating a program plan. These criteria give us general directions and things to look for along the way.

The overriding goal of all programs is to help the individual to survive in the most normalized environment possible for that person. Survival is thus defined as effective coping with the environment rather than simply the preservation of life.

An important aspect of coping is the ability to control the environment and to make choices among alternatives. In other words, we make life work for us by controlling our own behaviors in our social and personal environments rather than being passively controlled by the events and things around us. Retarded persons should, therefore, be helped to develop behaviors which will extend their effective control over day-to-day situations involving other persons and themselves.

A second criterion directly related to the foregoing is that goals should be selected which will lead to increasingly complex behavior. The desirability of fostering complex patterns of behavior is illustrated by the fact that such behaviors are more frequently demanded now by our technological and increasingly sophisticated society. Hence, developing complex skills, such as fine finger and hand dexterity or better communication skills, increases the individual's control over the environment, thereby improving his probability of survival. For example, the retarded person should learn skills necessary to begin taking advantage of the more complex opportunities available in American society instead of remaining totally dependent on others throughout his life cycle.

The third, and in some ways the most basic, criterion for determining programmatic goals is the concept of maximizing the human qualities of each individual. By "human qualities" we mean those behavioral characteristics which are culturally designed as "normal" or "human." Obviously, these characteristics differ from culture to culture and from era to era within the same culture. Failure to comply with cultural standards may seriously impair, or totally ruin, the individual's ability to cope with this environment — sometimes resulting in rejection, isolation or even loss of life. Indeed, the popular strategy of institutionalizing retarded individuals is a direct result of their failure to conform to cherished cultural values.

Our culture defines relatively flexible boundaries for behaviors considered acceptable during most stages of development (such as infancy, adolescence and adulthood). The individual whose behavior consistently violates cultural expectations may be labeled as "deviant" and is in danger of social isolation. For retarded persons then, this principle implies attempting to develop behaviors which are appropriate to the individual's stage in the life cycle.

Maximizing human qualities should not be interpreted as a sterile, mechanical procedure resulting in puppet-like individuals who unthinkingly mirror socially established patterns. On the contrary, human qualities include such attributes as the ability to determine one's own daily and long-term objectives, as well as the strategies to accomplish them. Humanness includes spontaneity, enthusiasm, initiative in interpersonal relationships and many other behavioral characteristics judged desirable by contemporary society.

PRINCIPLE eleven

Programs for mentally retarded persons should utilize the community's existing services to the fullest extent.

In a fascinating study of the community adjustment of deinstitutionalized mentally retarded persons, Elinor Gollay and her associates discovered several important relationships between successful community adjustment and existing community services. Those individuals who had the opportunity to participate in more community programs and who received more of their needed services from local community agencies made better adjustment and were less likely to return to institutional settings.

In general, those who made a successful adaptation to community living appear to have been more actively using community support services and training, participating in day placement activities and enjoying leisure time pursuits and friendships.

Evidence from the few formal studies available all underscore the validity of Principle 11. "Specifically, mentally retarded persons living in communities which have a wide range of services, training and residential options available do better than those mentally retarded people living in less supported communities. The more support available in the community the more likely is the mentally retarded person to remain in the community, to be more active, to have fewer problems, to have more independence, and to have fewer unmet needs," according to Gollay, Freedman, Wyngaarden and Kurtz.

PRINCIPLE twelve

A comprehensive system of community services must be developed to provide for:

1. Early identification of handicaps which are developmentally disabling;
2. Early assistance to correct or alleviate those disabilities and the establishment of a continuity of services to thereby reduce the need for residential services; and
3. Ongoing services to the individual and family to assure the greatest possible gains in development.

There is a fairly widespread and understandable confusion about the meaning of a "comprehensive system of services." Webster's dictionary defines comprehensive as "inclusive" and "covering completely." A comprehensive community service system would, therefore, be one which was able to respond to any service need presented by a citizen of the community.

Three types of services are particularly applicable to mentally retarded individuals and their families:

- **Identification** — It is especially important that we identify every child who has some handicap which could cause mental retardation. Identification of these children should occur as soon after birth as is technically possible.

- **Assistance** — When a handicapped or disabled child is located, a service system should respond without delay to correct the disability or reduce its impact on the child's growth and learning. Evidence from successful infant development programs indicates that many of the disabling consequences of disease, birth defects and brain injury can be significantly reduced if recognized early. These infants, therefore, are less likely to require extensive, complex and costly services later in life.

- **Ongoing Services** — When helpful ongoing services are available to the individual **and** his family, there are fewer complications in the continued development of that family. When family members are helped to understand and successfully cope with a child's handicap, there is less likelihood of a need for early placement of that child in some type of residential program. Such early and continued services also reduce the incidence of family disruption and thereby provide a more constructive home environment for the personal development of all family members.

PRINCIPLE thirteen

Community services should be strategically located throughout the state, region or county to promote maximum social integration of disabled citizens into the community.

Principle Number 13 relates closely to the foregoing principles. Observations by most social and behavioral scientists support the idea that mentally retarded and other disabled individuals should not be congregated in large groups but should be integrated with the mainstream of a community's life. Small groups offer greater opportunities of all kinds.

In order to achieve this goal of integration, it is necessary that services and facilities be dispersed throughout the community. It should be stressed, however, that dispersal **does not** imply isolation or lack of coordination and supervision.

In conclusion, let us say that a clear understanding of these 13 principles is fundamental to deriving the full benefit from the rest of this publication. Programs which are governed by these principles afford mentally retarded people more constructive opportunities than programs planned in any other manner.

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3

GOALS OF RESIDENTIAL PROGRAMMING

When we speak of residential services, there is a tendency to think of only one or two approaches, such as total institutions or group homes. In reality, there are many ways to provide residential services and each of them may be appropriate to some individuals at a specific point in their lives, while being inappropriate for others. It would be beneficial, then, to organize our thinking about what a residential service is and to explore the variety of alternatives now available.

This chapter will attempt to clarify the nature and function of a residential service and to provide an overview of several fundamental issues which influence its impact on individual development. We will explore the way residential services reflect the community where they are located and the role they play in meeting the basic human needs of their clients. We will also briefly examine current knowledge of human stress as it relates to the design and operation of a residential service. These discussions will be drawn from evidence presented in scientific literature, but for ease in reading, not all references will be noted in the text.

For the purposes of introducing a discussion of residential programming, it is perhaps sufficient to simply list some of the major alternative approaches. The specifics of these alternatives will be given in **Volume II: A Continuum of Residential Services.**

The simplest, although not necessarily the most appropriate, way to quickly organize the various program options is by age, developmental level and health status. Therefore, within each major age category we may make further divisions to account for the extreme effects of developmental level and health status. There are, for example, programs and facilities for children, adolescents, adults, the elderly and, finally, special purpose programs and facilities to meet specific needs of residents for short-term intensive training. Intensive training programs may be designed to teach vocational skills, basic self-help skills or to modify anti-social behaviors. In addition to these options, we are also interested in programs for those persons with intensive medical and nursing needs.

The level of training and guidance needed by each resident is the determining factor in choosing a specific type of facility. All residential services share one overriding priority. They are homes. They are places where an enormous amount of learning takes place.

A home represents many things to each of us: social psychologists call it the "primary environment," and home is often thought of as our territory; it's the place where we engage in the most basic and perhaps the most important activities of living. Our homes are much more than a place to sleep and eat. Homes represent a fundamental focus for our personal security, a place where our physical, emotional and other psychological needs are met. Home is probably the most important environment in our lives. As we shall see in later discussions, our home life influences everything else we do — our health, our school work, our vocational success and our ability to deal constructively with other people and to function successfully within society. All of these things are intimately related to what happens to us in our home.

Also, bear in mind that calling a residential service something other than a home does not alter the fact that it is a home for its residents. Length of stay does not determine whether or not a place is a home.

A Microcosm of the Society

A residential service is, or should be, a microcosm of the larger community. That is, the residential program should be an abbreviated, but typical, representation of the community or society in which it is located. There is nothing particularly unusual in this requirement since social scientists have for many years observed that successful families are always microcosms of the culture in which they occur. It is, however, an important concept since residential programs easily fall victim to becoming isolated entities within, but unrelated to, the mainstream of community life and, occasionally, unrelated to the needs of their residents.

We expect those in programs that are microcosms of the larger society to be continually challenged to solve the same kinds of problems other community residents face. Even while recognizing the reality of severe mental retardation and the

MAJOR CATEGORIES OF RESIDENTIAL SERVICE OPTIONS

RESPITE SERVICE
Temporary care outside natural home.

SUBSIDIZED NATURAL HOME
Monthly stipend provided to help family avoid need for out-of-home placement.

FOSTER HOME
May be referred to as Family Care and includes clients of all age and developmental levels.

GROUP HOME
Category includes a wide variety of operational models serving all age groups and all levels of disability. Group size and level of supervision varies with severity of client's disability.

APARTMENT
Category includes a variety of operational models serving primarily adults. Level of supervision varies according to client's level of independent living skills.

TRANSITIONAL INTENSIVE TRAINING HOME
Facility for clients in need of intensive training prior to placement in other group-living program.

SPECIAL NEEDS FACILITY
Category includes such specialized programs as those for multi-handicapped persons, or individuals with severe behavior problems.

NURSING HOME
Primarily a facility suitable only for persons with serious and chronic medical problems requiring 24-hour skilled nursing supervision.

probability that not every resident will achieve the goal of independent participation in society, we should do our best to keep the individual moving toward that goal.

In every residential unit there are connections to the broader community. These connections may be in the form of television, radio, food supplies, recreation, clothing sources, laundry services, plus a host of other resources and services. The residential program director must take full advantage of these connections to provide appropriate challenges for teaching decision making skills so that the resident can learn to survive in this society.

Learning to Learn

Jerome Bruner, an internationally respected psychologist, has stated an important principle for teachers. The principle is drawn from Professor Bruner's massive research into the learning processes of children. He says that "any subject can be taught to anyone at any age in some form that is honest." For example, the basic principles and laws of physics can be taught in a series of playground activities, preparing the child to transform these experiences into more sophisticated knowledge of gravity, inertia, momentum, etc., as he is ready to use such concepts.

Professor Bruner has also concluded from his knowledge of human development that the first priority of the human mind is to impose order on the environment. The concept of establishing order is a useful bit of information for the residential program director. We establish order in our environment because it is difficult, if not impossible, to deal effectively with chaos. For example, through the development of language we bring order to a situation: objects, people and things are still assigned to mental categories and labeled. Without names for things we could not categorize objects or ideas, and without categories we could not organize information into useful knowledge. The development of language is essential to the mental process of organization, sequence and all other cognitive processes. A simple example involves putting away clean laundry. Think how difficult it would be to efficiently accomplish this task if we couldn't recognize and label a sock as "a sock" or a shirt as "a shirt." Or, to take the example one more step — if we couldn't match a blue sock with another.

Understanding Bruner's simple principle provides an insight into the organization of residential programming. To a greater or lesser degree, every resident needs opportunities to learn how to categorize information and impose order on the environment. The home is, of course, the ideal setting for learning and practicing such skills. For example, eating provides many challenges for imposing order. Available foods must be selected and prepared according to principles associated with good nutrition and cultural and individual preferences. The dining table is also organized according to cultural rituals. In fact, "setting the table" is often the child's first introduction to the sequence of organizing the environment in preparation for sharing a meal. The meal itself provides a setting for learning a sequence of social skills called "table manners." As you consider the organization of activities within the home, you can appreciate the enormous array of opportunities for learning.

In addition to the concept of imposing some logical order or organization on the environment, the concept of sequence is crucial. Understanding a sequence of events plus the ability to plan and follow a sequence are essential skills in the development of autonomy or independence. within our homes we establish various routines and activities which are designed to make our lives more comfortable, orderly, pleasant and efficient. These routines are established in some reasonable sequence so that a series of actions will more likely result in a desirable outcome. We have mentioned the sequential organization of meals, but consider also the sequence associated with getting up in the morning and preparing for a day's activities. The average person gets out of bed, attends to hygiene and toilet needs and dresses before going out of the house. Each element of the process also has its own sequence. Clothing is put on in some predetermined order. While there is flexibility in the exact sequence of many activities, there are certain logical constraints on the order of events, and we learn to take these limitations into account. For example, socks are put on before shoes, underwear before outer garments, etc. As average adults we understand the logic of these successive behaviors and appreciate the humorous, but socially disastrous, consequences of dressing in a random manner. We know that our social effectiveness is not enhanced by wearing socks over shoes or wearing undergarments on the outside of our clothing. We learned this logic, and the sequence involved, while we were children, and we learned it in the place where we lived — our homes.

An understanding of sequence is also essential to the development of most other skills in life. Schoolwork, vocational ability, recreation and social interaction all depend on our ability to follow a sequence — even if we never learn to fully appreciate the logic of the sequence.

The mentally retarded person in a residential program must have adequate opportunities to learn and practice these three pervasive areas of development: (1) language, (2) organization and (3) sequence. Initially, the individual can practice these skills most effectively when they involve daily routines which are personally meaningful and which result in some satisfying outcome. Clients within a residential program benefit most when their home environment is carefully structured to constantly challenge them to increase their organization skills, extend their use of language and to exert more individual influence on the environment in which they live.

Skills Training

During the past 20 years we have seen remarkable progress in the area of skills training for mentally retarded children and adults. By the late 1960s the use of operant or instrumental conditioning techniques, which had come to be called "behavior shaping" or "behavior modification," became a widespread approach to institutional programming. The behavior modification techniques, which are generally attributed to the research of B.F. Skinner, soon became the pervasive practice because they were found to be truly powerful means for shaping behavioral responses and teaching complex skills to even severely retarded persons.

Behavior shaping methods are based on a simple, but highly effective, principle — that of bestowing a reward when a specific desired behavior is performed. Actions are broken down into simple steps to be carried out by the individual, with the sequences eventually culminating in a set of desired behaviors which is then carefully reinforced by appropriate rewards of food, candy, toys, privileges or social praise. Likewise, those actions or behaviors which are deemed to be undesirable cause loss of reward. An unwanted or undesirable behavior may sometimes be extinguished or diminished by simply ignoring it since attention, even negative attention, from the teacher may sometimes be regarded by the resident as satisfying. Behaviors which have no satisfying outcome are usually discontinued. However, if the unwanted behavior is not diminished by ignoring it, some form of punishment may be used each time the individual demonstrates that particular behavior.

The use of aversive or punishing techniques raises a host of problems when applied within a residential program and is viewed with grave suspicion by many parents and professionals. In an effort to deal with these problems, in 1975 the Association for Retarded Citizens, National Headquarters, issued a set of **Guidelines for the Use of Behavioral Procedures in State Programs for Retarded Persons.** (See the Resource Section on page 108 for information on securing a copy.)

Operant conditioning techniques are essentially the same as those commonly used child-rearing practices which families have employed for centuries to encourage their children to behave in certain ways. The Resource Section (page 108) of this book contains a variety of references for the reader who wishes to learn more about the use of behavior modification techniques.

The knowledgeable and sensitive program director realizes that because behavior shaping techniques are such powerful tools in the teaching process, their use must be carefully structured into a total program. Skills which are taught outside of a total program are not only more difficult to achieve in the first place, but are also more likely to be lost once the active training stops. One of the truly frustrating, and all too common, experiences of those who work with mentally retarded persons is that of watching remarkable progress in self-help skills among groups of severely retarded youngsters, only to see rapid regression and loss of skills when the active training stops. Further discussion of planning goals and program structure is included in Chapter 6.

Problems of Consistency

The scientific literature, in which studies of training and teaching methods are reported, can provide several useful insights into why so many programs fail in the long-run, as judged by whether or not a person retained the new skills and used them regularly in his daily routine of living. Perhaps the two most frequent complaints from directors of behavior modification programs relate to staff proficiency and design of the environment in which residents live.

The literature on child development and on teaching mentally retarded persons recognizes that consistency in both content and method exert strong influences on how effectively a person learns new skills. The mentally retarded person is especially vulnerable to inconsistent approaches to training because he has special difficulty in recognizing relationships between separate events and between words and actions.

Since consistency in training is of such crucial importance in a behavior shaping approach, anything which interferes with or blocks that consistency endangers the successful learning and retention of new skills. The house managers, in-home teachers or direct-contact personnel, therefore, have the major responsibility for assuring program consistency for each resident. If any member of the staff is ignorant about how the training method is used, or if there is misunderstanding about which behaviors to reward, then the chances for successful retention of a new skill are more remote. Also, in programs which suffer frequent staff changes the resident is exposed to major disruptions in consistency and is, therefore, less likely to retain new skills.

An environment designed for large groups or one with a variety of physical barriers can also destroy consistency. If, for example, the resident is being trained to become independent in going to the toilet, he is doomed to failure if he can't gain physical access to the toilet. Or if the group is too large to permit sufficient individual attention to each resident's progress in learning and practicing the new skills, consistency can be interrupted.

Aside from the specific problems related to various training techniques, there appears to be a more global problem associated with many residential programs. In an examination of individual program plans we often find that a new skill will be taught without enough thought being given to how it fits into the resident's daily life, extends prior learning or contributes to the gratification of fundamental human needs.

For many years we struggled to incorporate successful skills training methods into residential programs, but now that such methods are generally available, it becomes obvious that skills training is only a part of the program — not its totality.

The mentally retarded person has the

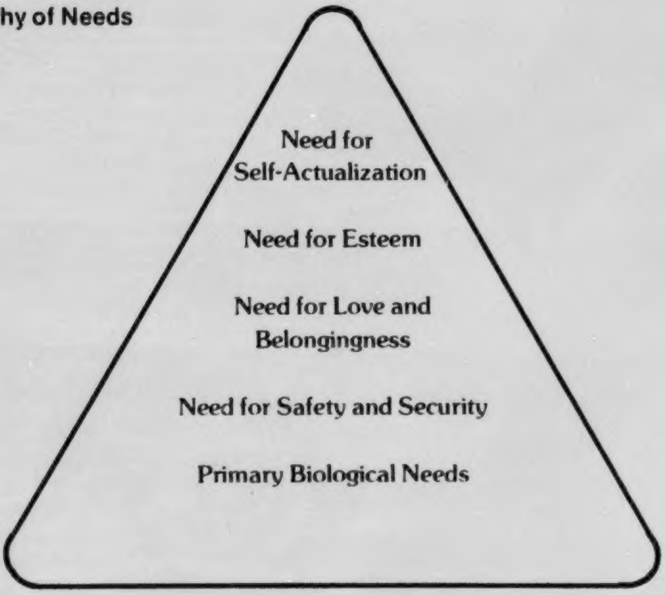
same developmental needs as all other people, although he may be much less adept at satisfying those needs. There is no scientific evidence to suggest that the retarded individual's sequence of basic human needs is altered as a result of being mentally retarded. There are, of course, those instances where overwhelming nervous system damage prevents interaction beyond a semicomatose state, but those are rare conditions and even then, our understanding of the human mind is still too limited to comprehend that person's potential for further development.

Human Needs

In order to gain greater understanding of how the program in a residential facility influences the success or failure of its residents, it is helpful to consider some of the major influences which directly affect resident progress. While there is controversy among psychologists about the exact nature of basic needs, there is majority agreement that people are motivated to satisfy certain internal demands before they can devote sustained attention to other behaviors. When basic needs, or drives like hunger, are poorly satisfied, constant frustration dominates other possible sources of motivation. In the following discussion, we will briefly examine one approach to viewing the residential program from the perspective of individual needs.

The late Professor Abraham Maslow conceptualized five levels of human needs arranged in a sequence which has come to be called MASLOW'S HIERARCHY OF NEEDS.

Maslow's Hierarchy of Needs


Need for Self-Actualization
Need for Esteem
Need for Love and Belongingness
Need for Safety and Security
Primary Biological Needs

How then can Maslow's Hierarchy of Needs improve our understanding of residential programming? Since these needs are inseparable from the whole fabric of living, it is logical that every aspect of the residential program must take them into account for each resident. Review again the levels of need and consider how a residential program should account for these fundamental influences on development.

LEVEL 1:
Physiological Needs

Hunger, thirst, sleep, waste elimination and breathing are examples of physiological needs and are often thought of as basic life drives. These are universal needs, common to all people, but in the presence of physical handicaps which are often associated with mental retardation, the individual may require special assistance to assure that they are met. For example, when a resident is hungry, distended by constipation or has difficulty breathing because of constant respiratory infections, he is less able to devote attention or interest to any learning task and has little motivation to do anything which does not directly relieve his physical distress.

LEVEL 2:
The Need for Safety and Security

Level 2 needs include safe shelter, familiar surroundings, a sense of home, protective clothing, physical comfort, security from physical threats from other people and security from loss of personal property. Whether or not an individual feels a sense of security in his home environment is critically related to his future personality and competence in dealing with people and with developing new skills. Both children and adults feel anxious in an unpredictable and unmanageable environment.

LEVEL 3:
The Need for Love and Belongingness

Companionship and exchange of feelings, the desire for others to care and the desire to care for others, charity, hospitality, congeniality, social adaptation and a feeling of comradeship are examples of Level 3 needs. When both physiological and safety needs are adequately cared for, there emerges a longing for love and affection, for closeness and a feeling of belonging. The individual, young or old, keenly feels the absence of friends, a sweetheart or a spouse, as the case may be. Residential programs generally have given too little attention to this level of need among their residents. Program directors must strive to develop that sense of family which provides a foundation for the development of personal and group identity and meets the human need for companionship.

LEVEL 4:
The Need for Esteem

A still higher order of need is that for the esteem of others and for a sense of self-respect and personal adequacy. This need may express itself in a desire for achievement or in a demand for recognition. Satisfying the need for esteem leads to self-confidence, while thwarting of it results in feelings of inferiority and helplessness. Our sensitivity to these Level 4 needs will result in guiding the individual to make those choices which increase his ability to contribute to his immediate environment and to become aware of his own significance as a member of his family and of the community.

LEVEL 5:
The Need for Self-Actualization

Even in instances where all of the foregoing needs have been satisfied, the individual may experience a sense of discontent and restlessness until he has had the opportunity to accomplish useful tasks for which he is (or may be) prepared. Self-actualization may refer to the need to experience life, the need for happiness, autonomy and self-determination. The residential service should provide opportunities for the resident to learn and successfully perform appropriate tasks to meet these needs.

It is, no doubt, evident at this point to anyone who works directly with mentally retarded individuals that gratification of all these levels of needs for every individual represents a considerable challenge. However, awareness of these needs and an effort to meet them to whatever extent possible can only enhance the programming in a residential service and improve the quality of life for its residents.

Most studies of human behavior support Professor Maslow's original suggestion that the individual who feels safe, who has a sense of belonging and who is loved will manifest more adequate adjustment than a person who, although he possesses both feelings of safety and belonging, has been rejected by individuals who mean much to him. Even more satisfactory adjustment presumably will be in evidence if the individual, in addition to experiencing the need-gratification indicated, has won the respect and admiration of his peers.

Effects of Stress

When a specific need is not satisfied, we naturally become frustrated. The degree of frustration experienced by a resident is highly individual, depending perhaps on earlier experiences with frustration and on the level of need in question. Anxiety is a consequence of frustration in satisfying basic needs, and mild anxiety can often become a source of motivation. If the degree of anxiety does not become too high, the resident's rate of learning may be increased in the presence of mild anxiety which is associated with the information or skill being learned. When an individual feels anxious about a situation, he is more apt to seek some solution to the problem in order to reduce his anxiety. If, however, he is unable to solve the problem, or to satisfy some primary need, his anxiety continues to build until it becomes disabling. Disabling anxiety results in a state of helplessness, with the individual depending totally upon others to make decisions and to care for primary biological needs. Prolonged intense anxiety prevents learning, interferes with the use of skills already learned and produces rapid deterioration of one's state of health.

We know surprisingly little about specific responses to anxiety among mentally retarded individuals because virtually all the research has been with non-retarded populations. But, there are no indications that retarded individuals experience anxiety any differently than their non-retarded peers. There are, of course, behavioral differences in the way some retarded adults show their anxiety as compared to non-retarded adults, but this may be related to the retarded individual's previous experiences and level of emotional maturity rather than to a fundamental difference in the effects of anxiety.

The middle-class businessman's anxiety over loss of his job can represent an extraordinary threat to his basic security. He may lose his home, personal property, comfort and food. How successfully he has satisfied those needs in the past and thereby learned to cope with such threats will determine, in large part, how he reacts to the present threat of losing his job. The retarded person is subject to similar threats to his security needs. The threatening situations may be less complex, but the effects of anxiety are the same, and how the retarded individual copes with that anxiety is also determined by how successfully he has satisfied those needs in the past.

Stress and the anxiety it produces are important considerations as we pursue the influences affecting a developmental approach to residential programming. The old cliche' about a man's home being his castle has persisted in our culture because it has meaning. Common law has evolved around the sanctity and privacy of the home. Our Constitution and Bill of Rights contain specific guarantees about the security and invulnerability of our homes. We invest a great deal of ourselves in our homes because that is our security base. Home is the place where we retreat from stress and try to cope with our anxieties. When the home environment is not supportive of our efforts to cope with stress, a chain reaction may begin which will interfere with our ability to function well.

When people experience anxiety which they are unable to resolve, they not only become less productive or efficient in work and school settings, they also become less efficient in social situations. If the anxiety is continued over long periods, the individual begins to suffer illness symptoms which, depending upon the intensity of his anxiety, can result in a host of physical complaints, including headaches, high blood pressure, heart disease, asthma, diarrhea, constipation, stomach ulcers and even sudden death. There are studies which strongly suggest that several forms of cancer may be directly related to specific kinds of anxiety.

Other reactions to unresolved anxiety may include adaptations which result in the resident becoming more independent, adopting more infantile behaviors or simply withdrawing into a protective and reclusive shell. Personal stress among residents of our residential programs must be a primary concern as we design those programs.

We can say, with some confidence, that mentally retarded individuals are at a much greater risk for experiencing the destructive consequences of stress. Considering the relatively recent advances in our understanding of mental retardation, it is likely that a majority of individuals in residential programs have relatively low tolerances for personal stress. Whether this vulnerability to stress is a result of poorly satisfied basic needs or simply the result of some impaired ability to internalize and learn from experience is not clear from the research available to us. One can presume, however, that both factors are involved. We know, for example, that positive interactions between many adults and mentally retarded babies may be few because mentally retarded babies don't always respond by "playing" or "talking back" the way average babies do. The conditions under which basic needs are gratified may need to be exaggerated to assist the retarded person in learning from those interactions.

The retarded individual may also have fewer opportunities to practice and verify his experiences relating to personal security, his ability to affect the world around him and his concept of himself as a worthwhile person. As average children mature, they challenge and repeatedly test both parents and other adults to assure themselves that they are safe, valued as a person and able to rely on the affection and comfort of others in times of stress. The retarded child usually has fewer opportunities to adequately satisfy these same needs.

Conclusion

A residential service is much more complex than any of the relatively limited descriptions usually found in the literature. It **is** a place to learn specific useful skills and it **is** a place to live, but it's much **more** than these limited views usually offer. The reality of human behavior compels us to recognize the residential service as an environment which promotes and encourages the whole developmental process, not just some limited aspect of it. The residential service, for whatever period of time the client participates in it, must be a dynamic environment which responds to every person's total developmental needs on an individual basis. It must account for each resident's fundamental human needs as well as the need for learning specific basic skills which he can use to begin participating in the broader culture and express his uniqueness as a person.

In a residential service, the skills and understandings of many different professional disciplines are brought together to create a home situation which can be responsive to the multiple learning needs of mentally retarded children and adults. This convergence of professional skill and scientific insight is essential if we are to meet the needs of those mentally retarded individuals who require an extra measure of our attention.

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4

STAFF CONSIDERATIONS

What do we expect of the staff members of a residential program? Are they managers, counselors, caretakers, teachers, supervisors, chaperons, custodians or surrogate parents? Are they unskilled laborers, paraprofessional aides or are they professionals in their own right? In truth, we find examples of all these roles and status levels among staff members of residential programs. There is a bewildering array of functional job descriptions and titles for those persons who are hired to interact directly with mentally retarded people on a day-to-day basis within a residential service.

The administrative structure of a residential service exerts the primary influence on job descriptions and expectations for staff performance. There are, however, other influences affecting job performance which are equally powerful but considerably more difficult to control. Examples would include academic preparation and participation in training programs by the potential staff member as well as the social expectations, personal attitudes and past life experiences as the individual grew up in a family and a community.

Studies of residential staff yield information primarily about the more traditional institutions, although we are beginning to see more studies of small community-based programs as those services expand. In their book, **As Close As Possible,** Baker, Seltzer and Seltzer report on their study of about 380 community residential programs across the nation. While there is considerable diversity in staffing patterns and staff roles among the various types of residential programs, there are, of course, some significant similarities. The study concludes that staffing patterns "are largely determined by the philosophical orientation and size of the program."

For small group homes with ten or fewer residents, the most common staffing pattern involves a husband and wife team who live in the home. The couple usually has the assistance of three backup staff members who provide help at special times during the day, as well as weekend relief for the live-in couple. The average staff-to-resident ratio is just under one staff member for every two residents.

In group homes of between 11 and 20 residents, similar staff patterns occur with one or two live-in staff in addition to the husband and wife team. Often there are also extra part-time staff to help with cooking, housekeeping and maintenance. Staff-to-resident ratios in the larger group homes average about one staff person for every three residents, although extra part-time staff usually brings the overall ratio down to about the same as that found in smaller group homes.

Job descriptions for staff also reflect the philosophical orientation and size of the program. Aside from the potentially overwhelming task of records-keeping and household maintenance, staff job functions include teaching, counseling and acting as substitute parents. Each role reflects a teaching model.

If we accept the fundamental assumption that the purpose of a residential program is to assist the clients of that program to develop effective skills for a more personally satisfying existence and for living within society, then we must also accept the concept of staff members functioning as teachers. As we pointed out earlier, mentally retarded children and adults need consistent guidance and structure to learn life skills. The retarded individual who requires a supervised service cannot ordinarily learn these skills without the assistance of other people who will teach and help him learn. Staff members of residential programs accept that responsibility when they accept such a position.

Founders of the Achievement Place Project at the University of Kansas at Lawrence named their group-living programs "Teaching Families," and academically support the teaching role of their staff members by providing related course work and giving credit for it. History may well note the Achievement Place Project as precursor of a widely accepted role — the professional parent.

Developing the professional potential for family-oriented teaching as a bona fide profession appears to be a likely future in the provision of residential services. Whether this relatively new professional is to be the product of universities, junior colleges or specialized inservice programs remains to be seen. There are logical rationales for each approach depending upon the type of residential service involved and the needs of its clients.

The Successful Staff Person

Based upon direct observation, conversation with staff members and published studies, we can define at least four major characteristics of the successful direct-service staff member.

First, the individual is able to make a personal commitment to his role as a teacher — not a teacher in the formal classroom sense, but someone who is willing and able to help handicapped people learn and practice new skills within both home and community settings.

Second, a basic knowledge of human development seems essential for the staff member to successfully fulfill the teaching role. A fundamental understanding of the sequential nature of development and basic principles of learning will provide a foundation for planning and carrying out individualized programs.

Third, staff members must possess adequate skills and receive ongoing professional assistance as they try to determine an individual's learning needs and to identify proper goals which the resident, staff and other professionals can work together to achieve. There are, of course, many teaching and training strategies which staff members must learn. The teacher must be sufficiently skilled to take advantage of normal day-to-day events and activities which can be used to teach new skills or to practice current ones.

Fourth, the ability and willingness to communicate freely with residents and other staff are of critical importance. Because of the nature of their handicap, mentally retarded individuals often experience devastating barriers to communication with other people. In addition to an intellectual deficit, the individual may also have central nervous system damage which interferes with or prevents verbal communication. Typically, non-handicapped adults tend to avoid discussions of any depth with the retarded individual. The communication skills so desperately needed are, therefore, poorly developed due to lack of role models and opportunities to practice.

Burn-out

A number of observers have called attention to the fact that staff members who work directly with severely and profoundly handicapped individuals are at special risk for "burn-out." Burn-out is characterized by a decreasing sense of personal satisfaction in working with a particular group or within a particular setting. These staff members also experience reduced motivation to pursue difficult program goals. Usually those who experience burn-out resign or transfer to other areas of work within an agency. In some types of facilities, however, the staff member may remain in the work situation, functioning in a more or less mechanical manner with neither enthusiasm nor motivation to achieve program goals.

While we do not know all the facts about the causes of burn-out or about the personal/professional characteristics of those who experience it, surveys indicate that a surprising percentage of staff experience burn-out after about two years in an intensive program situation.

Robert Veninga, at the University of Minnesota, studied the burn-out syndrome while doing research into the relationship between work and health. What he found was that recognition for work is the prime motivator for most of us. In the long-run it even ranks above money. And, Veninga said, lack of recognition can lead to burn-out. So can "organizational pressures" as perceived by workers: responsibility without authority to accomplish the task, and responsibility without the resources needed to get the job done.

Most achievement-oriented workers will respond physically and emotionally to these "no-win" situations. "They can experience exhaustion, have headaches, wake up in the night thinking about the job, become depressed and, in acute cases, have chest and stomach pains," according to Veninga.

Veninga's research seems to indicate that those individuals who take an idealistic approach to their jobs have the greatest tendency to experience burn-out. Burn-out can, however, happen to almost any worker who sets high goals for himself and is stopped short of achievement. If residential program staff experience few successes in teaching new skills to their clients there is a strong tendency to develop a sense of chronic frustration along with all the other anxieties commonly associated with prolonged and chronic frustration.

Staff members give relatively consistent reasons for their decisions to resign or transfer out of a specific residential program. These are: (a) lack of administrative and educational assistance to keep the program successful and the residents progressing; (b) lack of personal and private space for live-in staff; (c) insufficient time away from the rigorous demands of active programs for severely and profoundly retarded individuals; and (d) low salaries that enhance the staff member's sense of being trapped in a dead-end job.

Since we all tend to withdraw from situations which we do not find rewarding, the phenomenon of burn-out is a problem of considerable magnitude in the design and operation of residential programs. These issues of staff satisfaction must be resolved if our programs are to have continuity and if retarded individuals are to continue their development.

A number of approaches have been suggested to support and motivate staff. It is fair to say in the beginning, however, that the effectiveness of these techniques has not been adequately studied. Therefore, we cannot conclude which technique or combination of techniques is best for any given situation.

When one considers the lifestyle associated with working as a live-in staff member, it is hardly surprising to learn that these staff commonly feel an acute lack of privacy. In most situations "they are practically never off duty because they have no other home to go to," according to Seltzer and Seltzer. In the majority of cases, the house staff have only a bedroom and possibly a bathroom to themselves. The bedroom may also serve as an office for records-keeping and household management activities.

While such a lifestyle may seem acceptable, if not exciting, at first, there inevitably comes a time when it is no longer satisfying.

Associated with lack of privacy is the complaint that serving as a live-in staff member results in a drastic reduction of personal time. For example, live-in staff have a reduced social life of their own and are less involved in activities outside the residential program. The Baker, Seltzer and Seltzer study also revealed that "over half the staff members interviewed have not taken a vacation since they began working at the community residence and those who had vacationed worked primarily in non-live-in settings." This particular staff problem represents a special dilemma for community residential programs.

The advantages of having live-in staff are easily seen. Live-in staffing arrangements provide continuity for developing personal and social skills among residents and are more likely to assure consistency of supervision and program management. Both of these factors strongly influence student learning and overall program success.

Another problem closely related to the privacy issue involves the practice of hiring married couples as live-in staff. While there are obvious advantages to having married couples serving as house staff, the evidence strongly suggests that it may not be such a good idea for the long-term success of the program or the marriage. The numerous divorces of ex-houseparents attest to the strains which can be imposed on a married couple. If the marital relationship is unstable, it creates a tense atmosphere in the community residence. Since most live-in couples are young and newly married, the likelihood of unstable periods is high as the young couple works out those marital adjustment problems which are common for most everyone. Also, if the couple resigns suddenly or leaves for a vacation, the residence is left with most, if not all, its staff gone.

The dilemma is that we have an effective

family-style situation which appears maximally beneficial to the program's clients but is apparently harmful to staff members. And the damage it does to married couples becomes, in the long-run, damaging to the residents for whom they are responsible.

There are two categories of solution to the problems associated with married live-in staff. The first category includes hiring only single live-in staff or using a shift work system in which there are no live-in staff. Many programs have found that single live-in staff can fulfill the necessary role models without the additional problems of marital stress.

The second category involves altering the circumstances which create or sustain personal dissatisfaction and marital conflicts. Considering the extreme difficulty of altering these circumstances, it is unlikely that many programs could financially afford the changes which would be required — increased private space and relief time from staff responsibilities.

There are, however, steps which can be taken to help alleviate the strain felt by live-in staff. The research relating to the phenomenon of burn-out suggests that we may at least be able to lessen the impact of work pressures and thereby lengthen the tenure of live-in staff. A. W. Parks has suggested that providing regular psychological consultation sessions for staff could reduce pressures and frustrations. Consultation should increase help with personal and professional conflicts experienced by staff in addition to programmatic and administrative problems.

Marvin Fogel at Northern Illinois University in DeKalb became convinced that people in the human services have a regular need to be rejuvenated. Fogel and a colleague, Ronald Rembisz, founded Human Service Consultants, Inc., in 1977. Since then they have presented many one-day burn-out seminars at private state-operated and community-based facilities. As part of the seminar, employees complete two questionnaires. One of the forms is a personal inventory "to help separate their work lives from their personal lives, work relationships from personal relationships and so forth. The purpose of this analysis is to make the person aware of how adequate his job is in terms of satisfying his emotional needs." A second form reflects an employee's job functions and the various factors which influence job performance. Rembisz says "the inventory can shed light on the stress accompanying any job function." Knowing where the pressures lie can increase an individual's ability to resolve conflicts and to cope effectively with frustrations.

Helping staff members to develop some meaningful involvement outside or unrelated to the residential program may be an important strategy to prevent burn-out. Outside pursuits might involve an enjoyable hobby, social or civic club activity.

Growing with the job is seen as one of the best ways to avoid being burned out. People who do this may have the ability to recapture the original enthusiasm about their jobs. Studies of personnel in other types of high stress occupations also indicate that keeping abreast of new developments in their occupation helps them to cope effectively with the frustrations of their work. This means, perhaps, that continuing education programs for staff may prove highly cost-beneficial if designed properly and used in conjunction with other strategies to reduce work tensions.

SUGGESTIONS TO STAFF MEMBERS FOR CURING BURN-OUT

1. Develop an active outside life with a variety of interests.
2. Personalize your work environment with meaningful pictures, objects, colors, etc.
3. Try for a transfer or put more variety in your job.
4. Take a vacation.
5. Try to change little things that gnaw at you and accommodate to those you can't.
6. Organize your time better so you can concentrate on vital tasks.

Marvin Fogel
Human Service Consultants, Inc.
DeKalb, Illinois

Selecting Staff

Like most other issues associated with staffing arrangements for small community residences, we have little useful data to guide us in knowing who to hire for a particular group of residents. Most program directors admit that they really have no reliable system for selecting staff beyond a reliance on their own intuitive response to the individual during a sometimes lengthy interview. One director in Wisconsin says that his interviews last from four to eight hours because there are so many different things he needs to know about the applicant and so many things the applicant needs to know about the job.

Many directors are inclined to prefer young staff, fresh from their college or university experience and willing to work for relatively low salaries. An often heard comment is that "these young people bring greater enthusiasm and creativity to the responsibilities of a staff member." Other directors, however, prefer hiring older individuals who have raised families of their own and who, they say, bring greater stability and maturity to the residential program.

There are logical rationales for each of the preferences and there are also particular problems associated with each age/experience group. It is likely that each staffing preference is appropriate for specific groups. Programs for adolescents and young adults may well require the enthusiasm and greater willingness to tolerate program risks that are more common to young staff. Programs for young children and older adults may function more effectively when staffed by older, more experienced individuals. There are, of course, many exceptions to such a generalized statement. It all boils down to carefully considering program demands and attempting to match those needs with the individual skills and experience of a staff applicant.

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ENVIRONMENTAL INFLUENCES 5

The Least Restrictive Alternative

Perhaps the two most influential concepts currently affecting the design of residential services are the social and legal requirements for (1) "active habilitation" (right to treatment) and (2) the right of the mentally retarded person to receive that treatment in the "least restrictive environment." We will explore the issue of active habilitation in Chapter 6.

The notion of a least restrictive environment frequently appears in professional literature and in recent legislation. It is, however, somewhat doubtful whether its meaning is uniformly clear to all or if it represents a unified course of action.

Ronald Soskin has reviewed the legal principles and court decisions associated with the concept of a least restrictive environment and points out the need for advocate awareness of the concept's effective use in the improvement of services. He also notes a need for further refinement of the principle.

In 1960 the Supreme Court enunciated the least restrictive alternative principle which arises from the Due Process Clause in the 14th Amendment. The Court stated that "even though the governmental purpose be legitimate and substantial, that purpose cannot be pursued by means that broadly stifle personal liberties when the end can be more narrowly achieved" (Shelton v. Tucker).

In the famous **Wyatt v. Stickney** (1971) trial, Judge Frank Johnson attempted to clarify the least restrictive alternative conditions for residents of Partlow State School by noting that it meant moving residents from:

(1) more to less structured living;
(2) larger to smaller facilities;
(3) larger to smaller living units;
(4) group to individual residence;
(5) segregated from the community to integrated into the community living; and
(6) dependent to independent living.

Several other court decisions later confirmed and established a legal requirement for providing services in the least restrictive setting. As Soskin points out, however, establishing the legal requirement did not resolve basic questions of applicability. "Did the principle refer only to alternatives actually physically available? Or, did the principle place an affirmative obligation upon the state to create new, less restrictive alternatives where not applicable?" Several courts have since expanded upon these issues making it clear that a person should be cared for in a setting which is the most appropriate to his needs as well as the least restrictive to his liberty. The fact that the state has not created such a setting or had not established enough such placements should not be a barrier to the individual's rights. Courts have now ordered states to proceed in creating less restrictive facilities, including the recruitment of foster parents who could provide suitable homes.

Even though the legal requirements seem reasonably straightforward, the criteria for judging whether or not a program alternative is the least restrictive continue to be debated. Many experts contend that alternative placements should be judged primarily on how well they provide the retarded person with normal life patterns and service methods available to all average community members. However, to many observers such criteria seem only partially satisfying when they consider service needs of the more severely handicapped person who may find the "normal" environment to be a significant barrier to his continued development. For example, certain severely retarded children, particularly those diagnosed "autistic," exhibit chronically high energy levels which create tensions that interefere with their ability to concentrate or to succeed in learning complex tasks. Studies have noted that as the complexity of a room was increased by introducing more objects and patterns, the amount of inappropriate behavior by these children also increased. If such responses to a normally complex home environment occur, then that environment can be considered detrimental to the continued progress of those children. Obviously, other approaches will be necessary to provide normalized experiences for such children, and efforts must be made to help them learn to adapt to normally complex environments. Another example which is frequently offered includes those modifications or departures from a typical, normal environment which are necessary to permit freedom of access for those persons dependent upon wheelchairs or other mobility equipment.

We can conclude that an application of "least restrictive" does not mean the same thing to every individual — that which is essential for the unhampered progress of one person may well be unduly restrictive to another person with other needs.

There does not appear to be a simple answer or standardized technique for determining the least restrictive alternative program for groups of handicapped people. There are, however, some very serious efforts underway to develop a more objective approach to determining the most appropriate residential setting for a handicapped individual. Charles Seevers and his colleague, Michael Trace, have devised a technique called the **Trace Matrix** which they believe can reduce the guesswork in placement decisions. The technique involves a graphed relationship between individual assessment data and residential service options. An individual's independent living skills are plotted in relation to that person's medical or physical needs and level of adaptive behavior. Use of the **Trace Matrix** then provides a quantitative determination of the level of restrictiveness required by an individual at that point in his development.

The basic assumption of the **Trace Matrix** is that individual scores from assessment instruments such as the **Adaptive Behavior Scale** (ABS) and the **Program Assessment Chart** (PAC) directly reflect an individual's level of need for restriction. Such an assumption is probably consistent with the assumptions we make about other forms of assessment and evaluation. As a society we have concluded that it is good to measure things because measurement permits us to be more accurate, effective and, thereby, more efficient.

At this point in time assessment tools, such as the PAC and the ABS, are only as accurate as our poor understanding of human learning will allow. There are, no doubt, many flaws yet to be discovered in the way these tools are constructed and used. The probability is also fairly high that our interpretation of specific test items may be erroneous. In spite of the many difficulties with test instruments, it appears that we can do a better job by using them than we can by not using them. The danger to be avoided lies in permitting the tests to become inviolable and unchanging. All assessments of human behavior are only approximate, and we must keep this concept of approximation always in mind when using any assessment tool.

A great deal of work is yet to be done in learning to use approaches such as the **Trace Matrix** to reduce the guesswork in deciding which type of environment is more appropriate for a specific person.

The least restrictive program approach must necessarily be individually determined. Since individual needs vary widely, a community's program options must reflect a capability of meeting this wide array of needs in a variety of settings.

Perhaps the most helpful approach to understanding which program options meet the requirements of a least restrictive alternative is from the perspective of the normalization principle. Normalization basically implies that the individual has opportunities to learn new skills, model or imitate appropriate social behaviors, make decisions, and learn and practice self-control. Normalization further implies that the individual has opportunities and assistance, when necessary, to achieve control over the way he responds to stimuli, the use of information and social interactions. If the environment encourages and supports the above opportunities in a manner which contributes to the continued progress of the individual, then we can assume that particular program environment is not overly restrictive.

Group Size and Personal Space

Does it make any real difference how many people live together in one setting? Do we know for sure what the best size is for a group home?

Yes, it does make a difference how many people live together; and no, we aren't sure about the optimum number of people for a group home, although we can make some educated guesses. There is considerable information available to us from biomedical research and studies in social psychology regarding the personal, social and health-related effects of crowding.

The old saying, "two is company and three is a crowd," illustrates our long-time recognition that crowding is a highly subjective experience. Some people seem most happy when surrounded by groups of friends, while others can tolerate even groups of friends for only short periods before they have to escape to a private and solitary place. There are several different personal factors and social situations which influence the way we respond to groups. There also appears to be an upper limit on the numbers of people who can live together over long periods of time without experiencing the destructive consequences of crowding.

During the past 20 years we have seen an increased interest among social scientists about the possible psychological effects of crowding. As is often the case, the early studies were primarily done with animals. Observations of severely crowded laboratory animals raised the possibility that humans might display similar behavior problems when crowded together.

If we are to understand the issues related to program and residential group size, we need to review the known facts about crowding. The information available to us comes from three types of research: (1) laboratory studies; (2) statistical analyses of crowded city areas; and (3) field research in specific settings such as jails, prisons, college dormitories, institutions and work settings, such as isolated offshore oil rigs. Each approach has both advantages and limitations.

Laboratory studies usually involve volunteers who are exposed to relatively short periods of crowding under different circumstances. While the laboratory studies have provided a number of insights into individual and group responses to crowding, they are generally thought to be inadequate for answering the questions we have about the design and operation of residential services due to the short periods of time involved.

Some researchers attempted to get around the problems posed by laboratory investigations of crowding by applying statistical analyses to relationships between various degrees of crowding in cities and certain indices of pathology such as mental illness, suicide, crime, physical illness, etc. Not surprisingly, several investigators have reported significant relationships between crowding and social problems such as juvenile delinquency and mental hospital admissions. However, their findings were rather weak and their statistical techniques questionable. The best one can conclude from these studies is that statistical surveys do not make a clear case either for or against the existence of negative influences induced by crowding.

The remaining basic approach to the study of crowding is the use of specific field settings such as dormitories, naval vessels, housing projects and prisons. These settings are more similar to the situations of concern to us in residential programs.

With one major exception, we have been unable to locate studies conducted specifically on the effects of crowding with mentally retarded individuals in residential facilities. Therefore, it becomes important to glean as much understanding as possible from studies of non-retarded populations. The effects of crowding seen in settings such as dormitories, prisons and housing projects can be directly applicable to our interest in space requirements for residential facilities.

It has been argued that people adapt to, or learn how to cope with, the stress of crowding over time. However, the studies of Dennis McCarthy and Susan Saegert at City University of New York indicate that perceptions of crowding become stronger the longer one lives in a crowded environment and that the social withdrawal caused by crowding within the home setting extends to other aspects of life. For example, residents of crowded housing projects appeared to become more alienated from the larger society the longer they lived in the crowded housing; they tended to visit friends outside the project less frequently, and they belonged to fewer social groups. These findings are consistent with observations from studies in other settings such as dormitories and suggest that the experience of crowding in such a personally significant area as our own homes can cause individuals to avoid social involvement generally. Crowded dormitory residents, like others in these studies, demonstrated more negative social attitudes which extended into their classroom and work activities. These should be sobering revelations to us as we consider the long-range social goals for residential programs in helping mentally retarded individuals achieve a more normalized lifestyle within our communities.

There are essentially two aspects of crowding which have significance for us. **Social density** refers to group size and **spatial density** refers to amount of space. Paul Paulus and his colleagues at the University of Texas at Arlington have examined the independent effects of group size and room size on an individual's ability to perform tasks which involve careful and sustained attention in a moderately complex activity. It was found that increasing group size or decreasing room size caused people to perform more poorly when they were subjected to either social or spatial crowding.

While spatial density (room size) has its obvious effects, the studies available to us suggest that it is social density (group size) which exerts the most harmful effect on behavior. In prisons, for example, increased group size led to a reduction in the individual inmate's ability to tolerate crowding of any sort. Inmates in dormitories housing 26 men, even where room size permitted up to 84 square feet per person, tended to be more socially negative, hostile or violent than did inmates in one- or two-man cells where space ranged from only 24 to 54 square feet per man.

We have known for many years that psychological stress has a direct effect on health. Therefore, if an individual's perception of being crowded causes personal stress, he is likely to experience illness more frequently as a result of that stress. Early laboratory studies on crowding indicated that it did not affect health, but the later field studies revealed quite a different picture. Illness complaints have been shown to be systematically related to psychological stress caused by crowding in situations as diverse as naval vessels, college dorms and prisons. It was found that illness rates for men living in prison dormitories were significantly higher than for men living in one- or two-man rooms. The researchers carefully studied the possibility that illness rates might be higher among dormitory occupants just because they were subjected to greater risks for contagious infections which spread among groups. However, the findings of the study indicate that infection risk was not a factor and the conclusion was reached that high social density induces stress that, like other stresses, can increase the rate of illness.

Earlier in this discussion it was noted that people seem to differ in their response to crowded situations. We are all aware of those situations in which limited space is associated with positive rather than negative behavioral consequences; for example, work situations in which the nearness of workers to each other enhances collective task performance or crowded parties which promote camaraderie among members of a group. Why, then, do people feel crowded in some situations and not in others? A major difference, of course, has to do with the length of time one is subjected to a crowded situation and the reasons, or goals, for the group. Neither work situations nor parties go on continually, and the rewards for group involvement (money or pleasure) usually sustain the individual's sense of security. If, however, we also experienced crowding at home, the work and party situations would rapidly become less rewarding and social or psychological withdrawal would become likely.

Daniel Stokols and his colleagues at the Social Ecology Program on the Irving campus of the University of California have conducted several studies which can provide useful insights for us regarding the perception of being crowded. Dr. Stokols investigated differences in psychological stress in uncrowded situations as opposed to those where the demand for space exceeds the available supply. People tend to feel stress when crowding is associated with real or imagined threats to their physical or psychological security. For example, the presence of dangerous or insulting persons would cause an individual to feel more intense crowding than the same degree of close contact with people who are not seen as threatening to one's security.

When an individual begins to feel the stress of having too many people around him in his home environment, those negative feelings tend to become associated with all of the person's other activities. There is, for example, a strong tendency for people who feel stressed by crowding at home to become alienated not only from their roommates or housemates but also from people generally. This sense of alienation can manifest itself in a wide variety of ways. For those who tend to respond to stressful situations by becoming aggressive, crowding is likely to generate combative and hostile behaviors at the slightest excuse. It is questionable, therefore, whether residents with severe behavior problems can ever be helped to control those behaviors as long as they live in an environment which they perceive as crowded. Similarly, those individuals who feel crowded at home perform less well in both classroom and work activities, tend to be more anti-social in their response to people outside the home and tend to have more illnesses.

One begins to see how the destructive effects of crowding can produce a cycle of problems for the group and failure for the individual. Dr. Stokols' research led him to conclude that "chronically unhealthy or unsuccessful students are more susceptible to (bothered by) crowding experiences and social problems than their healthy or academically gifted counterparts." If this is true, and all the research seems to indicate that it is, we must rethink our approach to admission criteria for specific residential groups. Those individuals who behave impulsively or destructively in response to frustration and anxiety may be better candidates for small, highly structured programs such as foster families or group homes for only three or four residents.

Group size is a critical factor to consider in choosing the most beneficial and least restrictive program for a mentally retarded individual.

Other Environmental Factors

In addition to group size, there are other environmental effects to be considered. Although we have less evidence to go on, factors such as color, light and sound may influence learning and comfort levels in ways similar to crowding.

Since the mentally retarded person's development is already compromised by inefficient or disordered thinking processes, we must explore every possibility to enhance learning through the effective design of his environment. If color or light influences an individual's ability to concentrate or to better organize his thinking, then we should put that knowledge to use, no matter how mild the influence might be. The total effort we make to positively control environmental factors could well make the difference in successful programs.

There is probably general agreement with the idea that light and color have an effect on us. However, when we ask "Why?" we hear mostly vague and intuitive reasons. We've come to believe that certain colors are cool, quiet and restful, while others are vibrant and exciting.

There are not many studies reported in the scientific literature which give us clear answers to our questions about color and light. Four separate studies between 1942 and 1968 all tend to agree that colored lighting influences judgments of time, length and weight. These studies discovered that red light tends to increase human reaction time and judgments tend to be overestimated. Green light, on the other hand, seemed to generate reactions that were slower than normal. Green or blue light also seemed to generate underestimation of time, length and weight. Thus, there appears to be some scientific support for our belief that certain colors are more soothing or more exciting than others.

The way a room is lighted may also be a significant factor for many handicapped people. Fluorescent lights have come under particular suspicion in recent years.

John Ott, president of Health and Light Research, Inc., in Sarasota, Florida, has studied the effects of standard cool white fluorescent lighting on classroom behaviors of children. This common type of fluorescent lighting also emits small amounts of X-rays and radio frequencies. Ott found, among other things, that standard fluorescent light tends to generate hyperactive and disorganized behaviors. Hyperactivity was greatly reduced by installing improved fluorescent lights containing not just the visible light spectrum but also the long ultraviolet waves that are present in nature. Lead foil shields were placed over the cathode ends to block the emission of X-rays while a wire grid screen encasing the lights was necessary to ground radio frequencies produced by the light.

Our understanding of hyperactivity or disorganized behavior is seriously limited, but there is increasing evidence which links these behavioral disorders with environmental factors such as light and sound radiation. The mounting evidence should cause us to rethink the lights we choose for living and working spaces.

In summary, we find that to make the most of the environment in a residential service, we must first determine what is indeed least restrictive for its residents and then try to utilize space, color, light and sound to make the setting as conducive as possible to the progress of these mentally retarded persons.

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6

PROGRAM DESIGN

There are numerous program guides for teaching general and specific tasks, and the reader is directed to the Resource Section on page 108 for a listing of several representative guides. However, in this chapter we will examine those program elements which tend to be missing from many of the published program guides. We will focus on the more fundamental developmental needs of the mentally retarded person and those aspects of learning which underlie the individual's ability to acquire new skills and to become a more successful and acceptable member of the community. The goal of this chapter is to help the parent or advocate to better understand the potential for program design in furthering the progress of the client in a residential service.

When we design life programs for other people, we shoulder a sobering responsibility. Within a residential facility, that responsibility becomes even more profound because our program decisions may literally control the total lives of those individuals entrusted to our care. Few professionals and even fewer parents have life experiences which prepare them to appreciate the need for the kind of vigilance as is required in making program decisions for mentally retarded children and adults.

Each of us, in the process of growing up, learned strategies for thinking, making comparisons of everyday events, solving problems and making reasonably successful decisions about ourselves and about our interactions with other people. Most of that basic learning occurred during our childhood years when every day was filled with curiosity and the exuberance of youth. How we learned to organize problem solving information is probably better remembered than how we met the fundamental emotional needs which permitted and supported the more formal aspects of learning. How did **you** learn to trust those significant people in your life? How did you resolve those questions about your security and place in the scheme of things? How did you meet the universal human need for self-esteem? How did you learn the value system which governs your decisions and gives direction and support to your interactions with the world?

Hardly anyone recalls those learning experiences with the same clarity as we recall learning arithmetic, spelling or other such skills. Yet the success or failure we experience in satisfying those basic needs which are common to humanity determines, in large measure, how efficiently and effectively we learn the skills of problem solving and social competency.

Skills training occupies a major focus for the majority of programs because skills are more easily measured and their presence or absence is more readily noted. For example, learning self-feeding or to control the bladder represents an immediate and sometimes crisis need for learning. A poorly developed self-concept, however, is not always recognized as a similar need for specific learning experiences.

Studies which examined the issue of self-concept, of both children and adults, reveal a fairly consistent relationship between an individual's internal, or subjective, view of himself and his efficiency in learning new skills. People with poor self-concepts are much more likely to demonstrate difficulty in mastering new skills. They also have fewer friends and are more likely to be socially incompetent. We do not yet understand exactly why or how this occurs, but there is abundant evidence that a definite and predictable relationship does exist between the satisfaction of basic emotional needs and the development of life skills.

It is significant that scientists, such as Abraham Maslow, Eric Erickson, John Nash and others, who studied these questions of basic human needs, have all related the satisfaction of basic needs to an individual's level of motivation. Those who fail to satisfy basic emotional needs are more likely to be poorly motivated to learn in other domains.

The whole question of motivation is still only partially understood, but it is repeatedly noted that one of the most frustrating aspects of teaching mentally retarded individuals is their tendency to be poorly motivated to engage in the necessary learning tasks. It may also be noteworthy that mentally retarded children are at great risk for failure in the satisfaction of basic emotional needs. The individual's handicap repeatedly distorts the ways in which he interacts with the people and things around him.

Perhaps we are inadvertently imposing an additional burden on the already handicapped individual and thereby making our tasks as teachers doubly difficult by our failure to give sufficient attention to helping the individual satisfy his fundamental emotional needs.

Teaching Self-Confidence

It is much easier for us to think about helping a child to develop a healthy self-concept than it is to think about some similar approach for adults. We are, however, faced with the responsibility of finding ways to teach healthy self-concepts to both children and adults. A healthy and constructive self-concept is reflected and influenced by the level of confidence an individual has in his own abilities.

There appears to be general agreement among psychologists and educators that an essential factor in the development of self-confidence involves having frequent experiences of success. If an individual has too few successful experiences, his motivation to learn and to be more independent is markedly reduced. Nor is the individual challenged to learn whose life is totally controlled to avoid failure because, in reality, he has no legitimate opportunities for either success or failure. Regular and meaningful opportunities to do something admirable, and to be recognized for it, appear to exert an important influence on developing self-confidence and a healthy self-concept.

One can readily see the evidence of this need for being successful in virtually any conversation with adults who are mentally retarded. Given the opportunity, they will tell you of some accomplishment which, in their opinion, merits your acknowledgement and hopefully your esteem. Non-retarded adults do the same thing — they are just a bit more sophisticated about it.

Programs then must be designed to meet the need for developing self-confidence and for satisfying a fundamental need for esteem. Fortunately, any training sequence can be structured to provide success experiences for the resident if we remain sensitive to the need.

Planning should also include individual opportunities for success in social situations, in community settings and in fulfilling vocational responsibilities. The way an individual thinks about himself, about his abilities and how he thinks other people value him will profoundly influence his personality, his ability to learn new skills and his success or failure in living within the community.

Self-Care

Teaching the mentally retarded person to take care of his own health and hygiene needs is always an important program goal. In our society, the person who looks or smells unclean is automatically at a disadvantage. People tend to reject or avoid individuals who appear dirty or unkempt. Children are often forgiven for looking unkempt, but adults are judged harshly if they fail to meet minimal public standards for grooming and behavior. There is little point in arguing the justice of such public responses because, reasonable or not, they are facts of social behavior. Although we can't easily change mass attitudes, we can prepare our students to overcome this inequity through our training programs. Therefore, every effort should be made to provide whatever assistance necessary to help the retarded adult maintain an acceptable state of grooming and hygiene.

There is also a relationship between self-care and one's self-concept. If people tend to avoid you or treat you with disrespect, your self-image is likely to be affected negatively and your self-confidence will inevitably be damaged by such experiences.

Perhaps no other area of development has received so much attention as that of self-help skills. There are literally dozens of published training curricula for teaching the retarded person self-help skills in areas such as toileting, dressing and eating. The Resource Section, page 108, contains several references to these available training descriptions. Having a training method, however, is only part of the task. Teaching self-help skills should be incorporated into a total program, involving language development and social skills as well as attention to the individual's emotional needs, self-concept and personality development. As has been noted earlier, the tendency to conduct single task training programs is one which should be resisted, since it is not an efficient approach in the long-run.

It has been assumed by many professionals that the retarded person can more easily learn a particular skill if that skill is taught in isolation. This assumption is based on the observation that retarded individuals tend to be easily distracted and, therefore, should focus their attention on only one task until that skill is mastered. Seltzer and Seltzer's book, **Context for Competence,** presents evidence that retarded adults who were given greater responsibilities and more learning tasks tended to perform a greater percentage of those skills regularly and independently. Such an observation should not come as a surprise since we've observed the same phenomena among non-retarded students for many years.

Edward Zigler and his colleagues have concluded from their research that we may be misinterpreting the retarded person's greater distractability. Zigler believes that distractability may not represent disinterest in the task, as we have assumed, but merely represents a style of problem solving which is rooted in a history of failure experiences. The retarded person may come to mistrust his own judgment and his ability to act appropriately. Zigler says, "Rather than utilize his own resources, which he learns to mistrust, the mentally retarded individual relies upon cues from others." Thus, what appears to be distraction may, in reality, be a method of assuring that someone else will intervene with guidance and assistance. If, however, more skills are taught, greater self-confidence may result in greater performance levels. Advocates and program personnel should carefully evaluate the nature of a resident's distractability to determine whether it is, as Zigler suggests, a learned strategy which has been reinforced over time by parents and staff. Hopefully, this program issue will be more carefully studied to determine the most effective combinations of skill-tasks and in-house responsibilities.

Language and Communication

One of the primary problems associated with mental retardation is a difficulty in learning language — language for thinking and language for communicating with other people. Several studies have noted that severely and profoundly retarded individuals often fail to learn language in residential programs, and in large institutional facilities there may even be a decrease in language skills among those individuals who were able to communicate when they originally came to the facility. Evidence strongly suggests that both of these problems are related to an inadequate understanding among staff members of language development.

The average person usually thinks of language in terms of people talking to each other. Talking is, of course, an important part of language, but not its only aspect. Many individuals with birth defects or nervous system damage may not be physically able to talk, but they may be able to develop highly sophisticated language skills and effective communication techniques. The use of sign language and language boards has proven highly successful in helping thousands of handicapped people to communicate effectively.

Language involves both understanding (comprehension) and effective use of that understanding (formulation). Comprehension or understanding usually involves both listening and looking. Handicaps such as deafness or blindness may limit one or both of these sensory receptors by which the mind gathers information about the world. A third major avenue of sensory input comes from skin and muscle sensations. It is through those skin and muscle senses that we must communicate with the individual who is both deaf and blind. Each of these avenues to comprehension should be considered when developing a program plan. Because mentally retarded persons may experience a variety of handicaps which interfere with comprehension, it seems wise to test every available approach in the effort to communicate intelligently. There is an impressive array of evidence that everyone learns more quickly and retains the knowledge more effectively if more than one avenue of sensation (sensory modality) is used. For example, seeing and hearing new information at the same time is more effective than either hearing or seeing alone. Learning is enhanced even more if touching and feeling are also employed.

No matter which sensory modality is involved, the individual must first learn to pay attention to what he sees, hears, feels or tastes. For the profoundly retarded person, a primary program goal is, of necessity, the generating of attention and increasing the selectivity of that behavior. In other words, we must motivate or train the individual to practice paying attention to a specified person, object or situation and then increase the length of time he can be attentive. Even the mildly retarded adult is likely to need guidance and assistance to improve his ability to listen carefully and pay attention to details.

As mentioned in an earlier discussion, people tend to limit their interactions with the mentally retarded individual partly because they find communication difficult and frustrating. For this reason, staff should give special attention to helping each resident practice his communication skills. Staff members must learn to listen just as they must help the resident learn to listen.

Finally, when reviewing program needs in the area of language development, it is important to avoid assumptions about a resident's ability to learn reading. There are reports of successful reading programs for even severely retarded individuals, some of whom also have multiple handicaps. As the person grows older, the ability to read, even minimally, will make a tremendous difference in the quality of life he can expect. Recognition of survival words such as *poison, stop, caution, walk, don't walk, no entrance, keep out, danger, men, women, ladies, gentlemen, etc.*, should be a priority of any program for children and adults who will be moving about within the community. We will return to this discussion of language in a later section on social skills.

Decision Making and Autonomy

It is not always easy to make decisions. Each of us occasionally has difficulty in choosing a new dress or shirt, or deciding what to fix for dinner or what to do in a crisis situation, or even who to vote for in a political election. We all have to make decisions of one sort or another many times every day. Perhaps everyone occasionally fantasizes about having someone else relieve him of decision making responsibility by making all decisions for him. The truth, however, is that human beings are predictably intolerant of having someone else decide everything for them. When one is deprived of the opprotunity to exert some control over his life through personal decision making, life becomes burdensome and personal motivation is depressed.

Mark, Angela and David had plenty to say about their interest in making personal decisions. Both Mark and Angela had lived for many years in one of the state's large institutions. David had lived in a nursing home for nearly five years before moving into a new state-operated group home with Mark, Angela and three other adults from the institution.

When asked whether or not it mattered when other people made their decisions for them or chose what they should do, Mark folded his hands and said, "Yes! Somebody always told me what to wear. I never did get to pick my own clothes. Sometimes everything would be too big and sometimes everything would be too tight."

"When my mother was coming to see me, I always got to wear nice clothes. Sometimes when I'd done a good job, Mrs. Allen would let me wear my red shirt — it was my favorite because my mother gave it to me for my birthday."

"Boy, they never did let me wear a red shirt," David grumbled. "We just wore pajamas or something all day. Everything had stretchy stuff like pajamas. When I got here and got money for working at the Center, first thing I bought a belt for my pants so you'd know I didn't have to wear pajamas no more. I got me lots of clothes now, and I can pick for myself what I want to wear. Sometimes I change clothes just because I want to — whether I need to or not."

Angela told of similar frustrations at not being allowed to choose her own clothes, but she was eager to talk about another area of decision making — food. Angela had only recently learned to cook, and it was an exciting and meaningful experience for her.

"You know," she said, "I never knew there was so many different kinds of things to eat. At (the institution) there wasn't enough money, I guess, because the food was pretty 'yukkey'. It was always sort of gray colored, and I used to wonder if somebody had chewed it up first 'cause it looked like somebody had. It was sort of mushy and cold. I knew food didn't always look that way 'cause I would see hamburgers and things at the canteen that weren't all chewed up. Hamburgers are so pretty, and they taste pretty too. They never did give us hamburgers 'cause somebody might choke on it."

"That's one of the best things about living here," Mark said. "You can help decide what to eat. When we go to the grocery store, I can pick out stuff that I really want, and I can even fix some of it myself. Cathy (house manager) helps us cook it if we don't know how yet."

Angela giggled and told of an incident where she had bought a coconut once on the way home from work and wanted to surprise everyone with it. She boiled it.

"Cathy sure was surprised," Angela laughed. "I didn't know you weren't supposed to boil it. I didn't know what to do with it to make it soft. But, it wasn't half bad — sure smelled good once we got it broke open. Cathy showed me how to get it out and grate it up for making desserts. I can make a coconut cake now whenever I want to," she said with obvious pride.

Every mentally retarded person may not seem capable of making his own decisions, but the truth is that virtually everyone can make decisions at some level. We learn to make decisions the same way we learn about everything else — by practicing at making decisions. And sometimes we make wrong decisions. The right to fail is also an important aspect of learning so that we can learn not to make that particular choice again.

Motivation to make constructive decisions is an elusive concept because no one fully understands how motivation works. We know a lot about things which influence motivation, and by using rewards, we can often motivate an individual to act in a certain way. For purposes of program design, some thought should be given to external (outside the person) motivation versus internal (inside the person) motivation. At the risk of being overly simplistic, we can think of these two aspects of motivation in the following way.

People may behave in certain ways only when they are told to do so by someone else, which is one form of external motivation. External motivation is usually generated by either reward or punishment. A great deal of our behavior is directly controlled by real or potential rewards and punishment. We work for external rewards such as money, social approval and the gratification of both spiritual and physical needs. We also try to avoid behaviors which are likely to result in social disapproval, punishment and loss of money or freedom.

When people are doing something because it provides its own reward or because they are interested or curious, they are said to be internally motivated. Satisfaction of that interest or curiosity becomes the reward. It is easy to see that if we are to successfully teach residents to become more independent, we must find more ways to encourage an internal motivation and to use external motivation judiciously. External motivation can be used, however, to develop skills which subsequently acquire inherent motivation. For example, bicycle riding or playing a musical instrument may require external rewards until a certain level of skill is reached, at which time performing the activity becomes its own reward. Acquiring such skills may be particularly useful, since they become sources of gratification which come under the control of the learner.

For many years, developmental psychologists have studied an aspect of motivation called "locus of control." Simply put, locus of control refers to whether or not an individual believes that he can influence the world around him through his own actions or whether he believes that the events of his life are controlled by other people and by forces outside himself (fate). Under normal conditions, the developing child learns that he is able to influence the outcome of events by his own actions. If an individual believes that rewards or punishments come to him because of the way he acts, he is said to have an internal locus of control. If, on the other hand, he feels powerless, that is, he believes that rewards are under the control of outside forces, he is said to have an external locus of control. A shift from external to internal locus of control appears to be essential if the person is to think about the results of his own behavior as either success or failure.

We are interested in this locus of control concept because studies show that both children and adults with an internal locus of control are more successful in academic and social development. People with an internal locus of control will be more persistent in completing a task, better able to delay gratification and more accurate in making moral judgments.

Of particular relevance to us in discussing program design is the observation that an individual with an external locus of control is less capable of imitating the behaviors of role models and is less successful in peer group relationships. He also has a more negative perception of teachers and authority figures, feels less responsible for his own behavior and is more apt to be maladjusted, delinquent and socially disruptive. These are behavioral patterns which are most likely to result in community adjustment failures and reduced opportunity for mentally retarded students of residential programs.

Fortunately, the evidence indicates that individuals can be taught that they have control over their own behaviors and, in turn, over their own rewards or reinforcement. Program design should always include opportunities to help the student recognize cause and effect relationships between decisions and the consequences of his behaviors. When programs are based on heavy use of external motivation, as in many behavior modification techniques, extra efforts may be required to establish an understanding that one does not always have to be told what to do — that personal decisions and choices can also result in rewards and reinforcement.

Mobility

In view of the foregoing discussions of self-confidence and learning to exert control over personal behavior, the need for individual mobility is an important program concern. The ability to move around within one's environment is necessary for continued development.

In the past, a lack of knowledge and technology doomed thousands of handicapped people to a short, sterile life because they spent it staring at a limited world from their beds or from the floor. Spending one's childhood imprisoned in bed increases the severity of mental retardation and assures a life of total dependence. Except in extremely rare cases, everyone can be given some degree of mobility even if it requires someone else to push the wheelchair.

The lack of mobility, however, is not limited to those situations involving a physical inability to walk. The need for mobility also includes the freedom and opportunity to move within the larger community — with or without wheelchairs and other mobility equipment.

During the rapid learning years of childhood, it seems especially important for the child to explore the world around him and poke into the way things are put together. Discovery of the shape, size and function of his home and its contents provides a basis for learning to use tools and learning to control his own behaviors.

Having a handicap does not interrupt the individual's curiosity or his need to explore that curiosity. Curiosity can be accurately thought of as "knowledge-seeking behavior." Being unable to move about and satisfy one's curiosity by seeing, touching and smelling is like adding an additional intellectual barrier to the present handicap. The opportunity to pursue curiosity is an important part of learning. Programs which capitalize on a resident's curiosity are likely to achieve program goals more rapidly than those which impose a predetermined structure on the learning process. Experts, such as Jerome Bruner, refer to these susceptible moments as a "readiness for learning," since teachers can exploit the resident's internal motivation (curiosity) to learn new information, new skills and more complex behaviors.

Regardless of the nature of an individual's curiosity, it can be utilized to teach **something** the individual needs to know. It can also be readily demonstrated that curiosity can be aroused in even the most severely retarded person. Bruner refers to this approach as "teaching a readiness for learning."

In behavior modification programs, the trainer may begin by stimulating the person's curiosity about the reward and how to get it. Once this initial curiosity has been aroused, it is possible to direct the individual's attention to focus on additional tasks. The individual's curiosity should be constantly stimulated and the ability to change locations, or move about, is a highly significant aspect of learning.

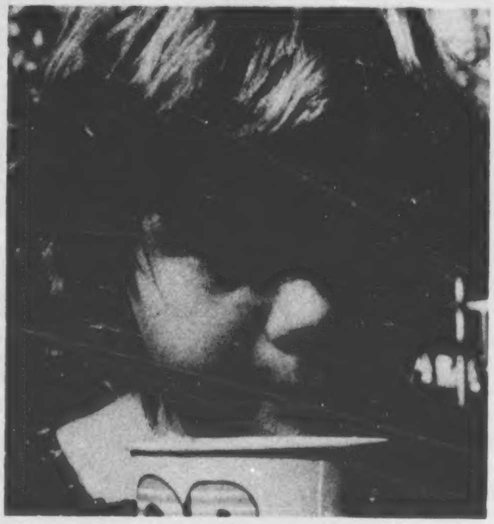
Mobility is an important functional component in program design. The following question should be posed for ever student during the program planning process:

"Does the resident have physical handicaps which interfere with independent mobility (i.e., blindness, orthopedic defect, cerebral palsy or other neuromotor defects)?"

If the individual does have a mobility problem, the next set of questions is:

1. What techniques or equipment are most suited to reducing or overcoming the mobility problem?
2. What new skills are necessary to use mobility techniques and equipment?
3. How can these skills be taught within the context of an overall program?
4. What compensatory experiences will be necessary for the individual who has severe mobility limitations?

You will find references to mobility equipment and training guidelines in the Resource Section, page 108.



If the individual is able to walk or has mastered the use of mobility equipment, the program plan should include regular excursions out of the home and into the community. With the advent of the Education for All Handicapped Children Act of 1975 (P.L. 94-142) most, if not all, school age children should be attending school programs outside the home. Adults, however, especially those with little or no experience outside the home or institutions, will need a structured program to teach them how to travel safely within the community — with or without supervision as may be appropriate.

Program directors should, of course, be especially sensitive to the fear and anxiety which a mentally retarded adult may experience while learning to use public transportation among large numbers of strangers. Such anxiety can usually be reduced through active involvement of the individual in helping to plan for the excursion. The individual's curiosity about some aspect of the experience can be generated easily enough and then utilized in an enthusiastic planning session.

Some program staff have helped residents construct large maps of a community and then used the map in regular problem solving games. These games teach residents how to find specific locations on the map and trace travel routes to and from their home. Such games can also involve lessons in safety, social manners and courtesy as well as what to do if the mentally retarded person gets lost.

Retarded individuals should also be given the opportunity to practice their knowledge of what to do in emergency situations. Such activities are essential for the semi-independent adult who is, or may soon be, ready to travel alone. Even those students who travel only with direct supervision should be regularly coached on how to behave in an emergency. Although unlikely, it is possible that the resident may wander away unnoticed or that something may happen to suddenly separate him from direct supervision. In such a situation, he should have some rudimentary understanding of how to seek assistance or how to protect himself.

There are normal risks in community life, but the willingness to take those risks is necessary if we are to succeed in providing good programs. Understanding the risks and preparing for them is the most effective way of avoiding them.

Social Skills

Throughout this book we have repeatedly underscored the importance of language development and learning to communicate with other people. The ability to communicate is perhaps central to the development of social skills.

Peter Mittler and his colleagues at the University of Manchester, England, have systematically studied the development of communication skills among mentally retarded individuals. Drawing upon his own work in England and that of Paul Berry at the University of Queensland in Australia, Mittler concludes that poor language skills among mentally retarded individuals are most often a result of our low expectations. That is, parents, teachers and other professionals fail to demand appropriate communication responses from the retarded child or adult. Mittler and Berry present compelling evidence that language performance can be dramatically improved by raising staff expectations for increasing communication skills, by demanding performance and by structuring an environment which encourages and facilitates optimum language functioning.

Direct demands for language performance can be done in many different ways. Imitation training has been identified by several authorities as one of the more powerful methods for getting severely retarded residents actively involved in communicating. Behavior modification approaches have also been devised to successfully motivate language development. It should be noted, however, that the ability of the individual to transfer language skills learned in one situation to a different situation continues to be an unsolved problem in many such programs.

While direct demand for language performance is probably an essential component of any program plan, we must not overlook an equally powerful tool — the environment. The ordinary everyday environment contains a multitude of opportunities to encourage effective language and communication. At the Fourth Congress of the International Association for the Scientific Study of Mental Deficiency, Peter Mittler and Paul Berry presented evidence for teaching language in an environmental context. They argued effectively for "a wider social and environmental context to language facilitation, a context concerned with the world of people, objects, and relationships, a context that will help people to express wants and needs, rather than merely phonology, syntax and semantics." Situations which involve choice and decision making provide poignant opportunities for language and communication performance. We can also be more resourceful in modifying the environment to give people opportunities for decision making — for expressing choice and preference between alternatives — for example, in choice of food, clothing, toys or activities. The opportunity to make choices and express preferences extends language and requires communication, while laying the behavioral foundations for socialization.

An individual's communication style and decisions play an important role in the development of successful social skills. We sometimes forget that retarded individuals develop attitudes and value systems the same way as everyone else. Those personal values and attitudes govern personal choices and social behaviors. Therefore, as language and communication are encouraged, cultural and personal values are also being learned.

There is often a rather awesome cultural gap between the social expectations within an institution and those within a typical community. Behaviors which may have been quite acceptable within the institutional society may be highly inappropriate in the community. For this reason, adults who are making the transition from institutions to small community-based programs may require special help in learning new values and social behaviors which are different from those which they previously found successful. We also frequently make the mistake of assuming that everyone who comes to live in a group or foster home needs only to learn a few specific tasks to be successful. That assumption works fairly well for the individual who has already learned those values which support acceptable social behavior. However, the individual whose value system lends little or no restraint to aggressiveness, dishonesty and immediate gratification will most likely fail to make satisfactory adjustments to community living.

A majority, perhaps, of group home programs teach independence and social skills through regularly planned interactions within the community. Residents are usually involved in self-care and grooming skills, shopping, meal preparation, use of public transportation, recreational activities and eating at restaurants.

Based on their observations and research at the Elwyn Institute, Rosen, Clark and Kivitz report that "while such programs may be successful in attaining general goals of increasing social competence and interpersonal skills, they do not deal directly with the remediation of inappropriate behaviors." In other words, on the surface, the mentally retarded person's behaviors may seem to improve, but this is not due to any core understanding of **why** the behaviors work or what they are based on. Socialization and community training programs are necessary, but "they are not sufficient conditions for habilitation when clients have learned more severe patterns of inappropriate behavior."

A recent survey of program directors and institutional administrators revealed that inappropriate social behavior was the most significant single factor causing retarded adults to fail in community programs and the primary reason for having to return the person to an institution or some more restrictive residential facility. We must, therefore, continue to search for teaching methods to assist these individuals in altering their current behavior patterns and learning those values which will serve to govern and direct more appropriate social behavior. Unfortunately, there is a dearth of well-validated therapeutic or behavior modification strategies available for this purpose. There are, however, some approaches which hold great promise in devising good programs.

The use of modeling procedures — capitalizing on the retarded person's ability to imitate adult behaviors — has been proposed by a number of experts as one of the more promising training strategies for developing appropriate social behaviors. Modeling and role-playing procedures are thought by many experts to have considerable utility for providing opportunities to observe and rehearse socially acceptable behaviors. According to the reports of Turnure and Zigler, role-playing and modeling are especially effective because mentally retarded persons tend to be "outer-directed" and highly dependent upon external cues for direction of their behavior.

The Individual Program Plan

According to Standards of the Accreditation Council for Services for

Mentally Retarded and Other Developmentally Disabled Persons:

"The individual program plan is a written plan of intervention and action that is developed, and modified at frequent intervals, with the participation of all concerned. It specifies objectives and goals and identifies a continuum of development, outlining projected progressive steps and the developmental consequences of services."

Accreditation standards, federal regulations, the ARC's national policy and accepted educational principles, all demand that an individualized plan for program services be developed for each person accepted as a client in a residential program. Here are some goals for such a plan:

- The plan should be based on individual assessment data and on any other data that can help us understand the resident's situation and his need for specific learning experiences.
- The plan should be developed by relevant staff of the agency or facility serving the individual, with the participation of the resident and his family.
- Regular review and modification of the plan is essential to meet current needs of the resident.
- Long- and short-term objectives should be stated separately and within a time frame.
- Objectives must also be expressed in behavioral terms that provide a way to know whether or not the program is successfully meeting its goals.
- Methods to be used in achieving the stated objectives should also be specified, and other agencies or programs capable of delivering needed services should be identified.
- The individual program plan must, of course, be modified as objectives are, or are not, attained.
- Review and appropriate revision of the plan should be a continuous and self-correcting process.
- The plan must help everyone concerned to coordinate his efforts and activities to assure maximum benefits to each resident in the program.

Setting appropriate goals takes into account the idea of providing an environment which enhances the logical sequence of behaviors and always builds upon previous learning. One must carefully consider the issue of programs designed to produce a specific behavioral act without regard for the logical sequence of behavioral patterns. Such approaches all too frequently ignore the long-term consequence of programming in favor of short-term gains, and we must all try to keep our focus on the long-term objectives. For example, the effectiveness and simplicity of behavior modification techniques can easily lead to their misuse if long-term goals and ethical concerns are not carefully explored. On the other hand, those who reject all behavior modification techniques are equally short-sighted since these approaches can be utilized in highly developmental ways — providing that we understand the consequences.

Developmental programming takes into account the sequence of behaviors and the characteristics of the individual learner. Consider, for example, those residents who are profoundly retarded. They must spend a life span with specific neurological problems, yet long-term objectives for these individuals must be both developmental and attainable.

Objectives for the profoundly retarded person should enhance his ability to make choices, achieve mobility and communicate with sufficient skill to develop human relationships and overcome barriers of isolation. Overcoming isolation is essential to the achievement of any degree of personal autonomy and intellectual development.

Severely and profoundly retarded persons are often dominated by impulses. Programs, therefore, should develop retarded people's capacity to delay actions and consider their potential consequences.

In assessing the learning needs of the profoundly retarded and/or multiply handicapped individual, it's easy to become totally overwhelmed by the global nature of his learning needs. If short-term, attainable program objectives are not worked toward, the parent or professional can be quickly frustrated and rendered helpless to employ his skills to help that person. Much of group programming probably results from this type of frustration. Where the learning needs are so global, the focus should probably begin with an assessment of what the individual student **can do.**

These are the components of such an assessment:

- Neuromotor assumptions (How much control does he seem to have over his motor behaviors? How much physical damage must be overcome?)
- Motor competency (What can he move and how efficient is the movement considering what he has to work with?)
- Sensory activity (How does he use his eyes, mouth, fingers, etc., and what evidence is there to suggest favorite routes of sensory input?)
- Perceptual competency (What does he do in response to various stimuli, such as voices and sounds, objects, your face and hands, various tactile stimuli, odors and handling such as holding, stroking, hugging, cuddling, etc.?)
- Problem solving (Does he reach for objects, turn toward sounds, respond verbally, communicate in any way? At more sophisticated levels, does he use tools in any way to pound or bang, to hold or retrieve, to feed himself, to amuse himself?) Is he able to solve even the simplest puzzle, such as locating or indicating the location of a hidden object, or follow directions and, at what level of competency?

Now, let us deal with **goals** as differentiated from behavioral objectives. Here are some definitions:

- Goals are broad, general statements of program intent.
- Goals benefit the resident because they provide direction for program development.
- Goals benefit the staff because they provide the basis for a coordinated effort.
- Goals inform the public because they are the tools of communication, telling the public of program intent.

- Behavioral objectives are descriptions of desired learning outcomes which include an observable behavior, a criterion and the conditions of performance.
- Behavioral objectives benefit the resident

because they provide a basis for evaluating individual learning.

- Behavioral objectives benefit the staff because they provide a basis for evaluation of staff effectiveness. Objectives also aid in the selection of instructional activities and materials.
- Behavioral objectives inform the public and concerned professionals because they communicate clearly what is to be learned.

Behavioral Objectives

Writing behavioral objectives usually sounds like a good idea to most parents and advocates, but the actual process of writing them is often confusing and difficult. Parents also complain that when they read the objectives written by program staff, they don't always know how to evaluate those objectives. Part of the problem in writing behavioral objectives is that we are not usually accustomed to speaking or writing with great precision. In our speech, we depend on implied general meanings, commonly understood relationships and innuendo to carry our message. When writing an objective, however, we must be exact, brief, and behaviors must be highly specific. Each objective must deal with only one new behavior. The behaviors we are attempting to achieve cannot be described in general or complex terms. There should be no doubt in anyone's mind as to the exact behavior specified in the objective. For example, saying that "the learner will improve his eating habits" does not give us the information we need. The statement could refer equally to grasping a spoon or chewing with the mouth closed — it is not specific enough.

Actually, writing behavioral objectives can be quite simple if you keep the following points in mind. A behavioral objective has three distinct parts — an observable behavior, a criterion and a condition. The "observable behavior" is usually fairly easy to identify, but we often become confused about "criterion" and "condition." Examine the following two charts, taken from the book by H.R. Padzensky and J. Gibson titled **Goalguide: A Minicourse in Writing Goals and Behavioral Objectives for Special Education.** Familiarize yourself with the elements of criteria and conditions. In the following two examples of behavioral objectives, one line has been placed under the "observable behavior," two lines under the "condition" and parentheses are placed around the "criterion."

Example #1

GIVEN PICTURES OF TEN DIFFERENT VEGETABLES,
condition

JOHN WILL NAME THEM (WITHIN ONE MINUTE).
observable behavior criterion

Example #2

SAM WILL REDUCE HITTING BEHAVIOR (TO ZERO)
observable behavior criterion

WHENEVER HE IS IN A FREE PLAY SITUATION.
condition

Conditions Chart

Time
Examples:
- within 20 seconds
- at regular intervals
- in the class period

Allowances
Examples:
- using paper and pencil
- with assistance
- given a number line

Restrictions
Examples:
- without assistance
- from memory
- without losing balance
- voluntarily provides information

Combination of Time, Allowances and Restrictions
Examples:
- voluntarily provides information
- from memory and using pencil and paper
- only when asked and within the class period

Criterion Chart

Per Cent or Number Correct
Examples:
- 80% of the time
- 4 out of 5 correct
- within 90%
- at least 6 times
- answers at least once
- successful each time (100% easily implied)

Time Limits
Examples:
- immediately
- within 5 minutes
- during the following week

Qualitative Descriptions
Examples:
- grammatically correct
- neatly enough not to require revision or doing it over
- extensiveness of vocabulary determined by the teacher

Finally, each objective for the program plan should fit into some overall scheme for individual development. It is helpful if a general matrix or chart is available to check current objectives against overall developmental needs. One should compare the program plan with a diagram such as "Maslow's Hierarchy of Needs" (see page 33) and with some type of developmental profile. One simple example of a developmental profile which still has tremendous usefulness was constructed in 1970 by Peter Hainsworth and his colleagues at the Meeting Street School in Providence, Rhode Island. Write each objective in a space next to the area of development with which it corresponds. Each program objective fits somewhere within the profile and gives a picture of those areas of development which are being fostered, while at the same time, revealing those areas of development which are not being addressed by the program plan. Other types of developmental profiles can also be used effectively, providing they are visually simple and include all areas of development.

DEVELOPMENTAL NEEDS			BEHAVIORAL OBJECTIVES
BEHAVIORAL CONTROL AND ADJUSTMENT	ORGANIZATION	**FOCUSING AND ATTENDING** (ability to select and pay attention to important cues in the environment)	
		ORGANIZING (ability to understand the nature of a situation and make appropriate plans for handling it)	
		MONITORING (ability to judge whether one's actions are accurate and appropriate and to modify actions accordingly)	
	SOCIAL SKILLS	**SOCIAL EMOTIONAL MATURITY** (awareness of needs of others, versus needing others always to meet one's own needs)	
		SOCIAL PARTICIPATION (degree to which individual establishes easy interaction with a wider range of other persons)	
INFORMATION PROCESSING SKILLS	VPM	Understanding Visual Information *(perception)*	
	LANGUAGE	Language Comprehension	
		Language Formulation	
	BODY AWARENESS CONTROL	Awareness of Body and Spatial Information	
		Efficient Movement of Body in Space	
COGNITIVE EFFICIENCY	LEARNING STYLE	Reasoning *(problem solving)*	
		Level of Effective Rewards	
		Independence in Group	
	CONCEPT LEARNING	Body	
		Direction	
		Time	
		Number	
		Size	
		Sequence	

Assessment and Evaluation

Recall that the goal of residential programming is to meet the individual learning needs of residents in that program. The question becomes, "How do you know what those needs are?" Some developmental needs are common to all people and, therefore, apply to every resident. Other needs are specific to the individual; that is, at any given point in time, each resident's need for learning and practicing a specific skill may be different. This is, of course, true for each of us — we all have our individual differences in the rate at which we acquire new information and master new skills. We learn new skills in response to the challenges and demands made on us by the events in our lives.

We discover the growth and developmental needs of clients by assessing their current skills and comparing their present abilities with some predetermined standards or with their own skills in other tasks or situations. If, for example, the individual has mastered basic self-help skills and consistently makes reasonable decisions about the routines of daily behavior, but knows very little about survival outside the protected environment of the residential facility, we can identify the kinds of skills he will need to take that next learning step toward greater independence.

There is a tendency to use the terms *assessment* and *evaluation* to mean the same thing. While both words have similar meanings, "evaluate" has a more specific implication for expressing an appraisal in some standardized manner, usually in numbers. A wide variety of tests, scales and behavior checklists assign a numerical value to the assessment process. For example, we are all familiar with the I.Q., which is based upon how an individual responds to a set of questions or tasks. The I.Q. is obtained by comparing the individual's score on a standard test with the way other people of the same age respond to the same tasks.

The disadvantage of these standardized, formal evaluation scales is that their high level of precision usually requires considerable time for administration as well as a sophisticated examiner. Also, there is an unfortunate tendency to misuse formal test data through inappropriate assumptions about their meaning. Because of these factors, formal evaluations are usually done only periodically. Assessment of individual progress, however, must be continuous on a day-to-day basis if the program is to be truly geared to individual needs.

Continuous Assessment

Continuous assessment isn't quite so difficult or idealistic a concept as some professionals are inclined to think. Perhaps it is only the way we've been thinking about assessment which makes it seem so difficult. An example of continuous assessment can normally be seen in the way parents assess their children. Parents usually become quite adept at monitoring and assessing the behaviors of their small children — knowing when to interrupt some behavior which is leading to an unpleasant or dangerous situation, noting with pleasure some new skill or understanding which has recently developed and providing encouragement for a difficult new challenge. Because of their sensitivity to the child and the resulting awareness of his behaviors, these assessments become a natural part of parent interaction with their children.

Carl Haywood has discussed some of the problems we face in the assessment of mentally retarded individuals and proposes a more useful approach to the whole issue of assessment. At the Fourth Congress of the International Association for the Scientific Study of Mental Deficiency in 1976, Haywood proposed that we develop assessment approaches which depart radically from the normative model. Normative tests are based on an assumption that all important human characteristics are generally dispersed among the population and that one can define "pathology" as some agreed-upon deviation from the average. Norms are determined by testing large numbers of children or adults and compiling a statistical average which then represents the "normal" child or adult. Individuals who differ significantly from this average may be labeled in some way which may or may not be valid on the basis of the degree and direction of deviation of their scores from the average score.

Haywood notes that common behavioral deficits in mental retardation can be categorized in the following ways: (1) deficiencies in intelligence leading to specific failure to develop important learning skills; (2) deficiencies in ability to appropriately adapt behavior to the environment which may be related to the expectations of other individuals; (3) deficiencies in personality/motivational development, coupled with intellectual deficits which may lead to inefficient learning styles; and (4) deficiencies in positive interactions with other persons.

There is no single normative technique, nor any combination of them, that is capable of covering this range of areas of functioning. To paraphrase Haywood, the behavior/social deficit associated with mental retardation is an ongoing developmental phenomenon and does not remain the same. This view creates a different set of assessment needs, and methods are needed to assess behavioral/social processes, rather than simply to catalog the successes or failures of the past. In addition, we need to look for outcomes that affect developmental programming rather than outcomes that have the goal of permanent classification of the mentally retarded person. Our goal is to **enhance development,** "to bring about a level of development that the particular individual has never experienced before. This is a goal quite different, for example, than that in the treatment of psychiatric illness, in which one seeks to restore the individual to a previously enjoyed state of health," Haywood says.

"The habilitation model of diagnosis is one in which the goal is intervention," he continues, and, therefore, the goal is not just to identify areas in which the mentally retarded person needs help, but to **find ways** of helping the individual in those areas. Assessment and intervention are intertwined deliberately so that some intervention takes place during assessment and assessment continues throughout the process of intervention, according to Haywood. "The habilitation model is not used to determine who will and who will not get services, but is used to determine which services are most appropriate for which individuals, for how long a period and what the most appropriate immediate objectives of those services ought to be. In other words, part of the goal of the habilitation model is to determine the desired person-environment fit, and then to help supply the processes for accomplishing that fit," according to Haywood.

He further points out that in the habilitation model, comparison is still used, but the comparison may be of the individual with himself over time, or across varying situations. Instead of determining how many items on a test the individual cannot complete, for example, one goal might be to determine how much help each individual requires in order to complete all the items.

The habilitation model of assessment also includes clinical procedures. "The first example is **neuropsychological assessment** which is a set of behavioral techniques for assessing the relative integrity of the central nervous system. In the hands of a skilled neuropsychologist these procedures enable one to compare the individual with himself in the strictest sense (for example, to compare the two sides of the body simultaneously) and to compare the individual with himself over time," says Haywood. "It is also possible to relate performances in different areas to each other; for example, to relate verbal and performance efficiency . . . . While it is quite possible and desirable to establish norms on all of these individual instruments, and especially to establish age norms for children, it is the skilled use and interpretation of these procedures that makes neuropsychological assessment a procedure for bridging the gap between normative assessment and the habilitation model. Especially in use with children, the principal goal of neuropsychological assessment is not to find brain tumors, but to discover educational methods by which the behavioral/social deficits that may be associated with central nervous system dysfunction can be overcome and the development of the individual enhanced."

Another example is **operant assessment,** or direct behavioral assessment. In this set of procedures, performance tasks are given to the subject and attempts are made to discover the environmental changes that will result in increases in the rate of desired behavior, or decreases in the rate of undesired behavior, according to Haywood. The assumption is that there is some optimal combination of environmental circumstances that can be applied to each individual instance of deficient behavior. Operant assessment is a particularly good example of the nature of assessment that continues through the process of intervention, Haywood says.

A third example of **clinical assessment,** he points out, is the commercially available set of teaching methods known as DISTAR. "This is a study-test procedure in which the level of achievement of children in areas of academic content is determined first, then teaching methods are applied, then testing is done again, teaching is applied, testing is done again, and so on. There is daily assessment of progress, and the assessment leads directly to the next step in the teaching and learning process. There are many such techniques available now. They all have the virtue of allowing children to compare their current performance with their own previous performance rather than to establish relative standing in a group. They all have the desirable characteristic of combining educational intervention with continuing assessment."

The last example given by Haywood is the **Learning Potential Assessment Device** (LPAD), a technique for assessing a number of the cognitive operations that are necessary for relatively complex learning and for relating performance in these areas to specified educational intervention techniques. An important characteristic of LPAD is that the students always succeed. "The goal is to establish how much help and of what kind might be required to bring about successful performance in the various areas of cognitive function that are examined. Another characteristic of LPAD is that its goal is **enhancing development** rather than either classifying or treating disease. It has the advantage of being followed by a set of educational techniques, known as Instrumental Enrichment (IE), designed to enhance development in the very areas of cognitive deficiency that have been identified by the LPAD. A further advantage is combining assessment of intellectual functions, adaptive behavior and personality/motivational development in a single instrument. Use of the technique requires a highly skilled clinician and its interpretation is not done by referring to a table of norms."

Assessment of Developmental Needs

In spite of the fact that we've made great advances in our knowledge about human learning and development, we are still surprisingly ignorant about ourselves. And, as usual, ignorance gives rise to conflicting opinions about the causes of certain behaviors and about whether a specific behavior is appropriate or inappropriate, constructive or destructive. Some people continue to feel quite strongly that society is best served by the removal of mentally retarded individuals from the mainstream of community life. However, such opinions, when applied generally to all mentally retarded persons, are incompatible with recent court decisions and interpretations of the U.S. Constitution and its guarantees of equal access to opportunities for every citizen — even those who are mentally retarded. Such isolationist opinions then become irrelevant since no private citizen has authority to deprive any other citizen of the opportunity to learn and to become a part of the larger society. The courts, however, have not yet clarified the responsibilities of state and local governments in assuring the services essential to fulfilling the constitutional guarantees of equal access to opportunity. Attitudes of isolation are, therefore, still fairly common, and they are important to the issue of assessment because such attitudes result in distorted interpretations when assessing behaviors. From the perspective of this isolation approach, behaviors tend to be assessed in terms of how well they contribute to the smooth functioning of a particular service or facility. Conformity, passiveness and strict obedience become valued behaviors in such environments. The scientific literature abounds with studies illustrating the results of isolation attitudes, and the consequences of these attitudes are not acceptable.

A similar distortion in the assessment process occurs when generalizations are made to all aspects of an individual's development on the basis of a single evaluation method. The intelligence quotient (I.Q.) is perhaps the most well-known example of an evaluation method which has been misused. There are countless examples of how a single I.Q. score has been used to make comprehensive assumptions about an individual's full range of abilities (even those not included in the evaluation) and his future potential as a human being. We are more sensitive today to these problems in the misuse of the I.Q. score, but other evaluation scales are equally subject to misuse and abuse.

It should be noted here that our misuse of any evaluation information does not necessarily impune the usefulness of that test or scale. Hammers, for example, can be used in many different ways, and not all of them are constructive. But, if you want to drive a nail, the hammer is a useful and valued tool. A wide variety of evaluation tools have use in our assessment process but none of them tells the whole story.

No assessment tool can stand on its own as **the** single method. One can recognize an anology between behavioral assessment tools and thermometers. The thermometer may accurately measure temperature but says nothing about the conditions which produced it or what it may be tomorrow. So, too, must behavioral assessments be interpreted within a context of the whole person and the challenges he faces. For example, the person with cerebral palsy or other neurological disabilities faces an enormous physical challenge just to communicate his mental or intellectual competence. A variety of assessment approaches are necessary, each complimenting the other.

As our technology improves and as our theories of human development provide more accurate explanations and predictions, the process of assessment will become more exact and, therefore, more beneficial to the person or social group being assessed. Also, as new program approaches are developed, our research methodologies will also change, yielding different kinds of data by way of sophisticated and rapid computer correlations between dozens of different behaviors and learning situations. While waiting for that day to arrive, we can work carefully, and with a fair degree of accuracy, using the methods and understandings currently available to us.

Assessment tools should draw a map of the resident's current state or ability in order for the teacher to move him forward. If they don't challenge the individual to learn, assessment procedures are empty and irrelevant psychological games. How useful is a city map which illustrates only part of the city with no indications of which roads lead to other neighborhoods or other cities? It would be a map of limited utility — good only to those individuals who weren't going anywhere. Most mentally retarded persons in a carefully designed program will move ahead at their individual speeds to fuller lives in the community.

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ACCOUNTABILITY

7

Each unit of the Association for Retarded Citizens has a statement of purpose in its constitution or by-laws. This statement of purpose usually contains some phrase such as "to improve the quality and availability of services to mentally retarded citizens." Just how this purpose is to be carried out, however, gives rise to a surprising number of divergent viewpoints, arguments and frustrations. To improve the quality and availability of services, it is necessary to monitor those services and to hold service providers accountable for the success or failure of their programs. Questions of accountability are fraught with emotional and legal side issues.

As one of many advocacy organizations, there is no question of the ARC's legitimate concern with the issue of accountability. In this chapter we will explore the rationale for monitoring services and examine some of the ways various groups have gone about doing so.

The Concept of Accountability

A fundamental principle of the American cultural and legal system is the concept of individual responsibility. United States citizens are held accountable for their actions; and in some situations for their inaction as well.

Accountability is so interwoven in our laws and cultural practices that we must account not only for specific things we do but also for specific acts we fail to do. We are accountable for our failure to act in situations which affect the "common public good," such as failure to report a crime, failure to stop and render aid or failure to report our income accurately. Our justice system has declared that ignorance of the law is no excuse for failure to act. A significant example of how knowledge of an event carries with it a social and legal liability is to be found in state laws relating to major crimes. If an individual becomes aware of criminal activity, he is required by law to report that information to some public authority — failure to do so makes him a partner in that crime. An individual is excused from personal accountability only when a court of law determines that he is incompetent to understand his responsibilities.

It is also noteworthy that all major religions have historically endorsed the concept of individual accountability. Individuals are believed to be subject to the judgment of God for what they do with their lives and also for what they choose not to do.

With these moral and legal sanctions, the principle of accountability has engendered a bewildering array of governmental agencies to regulate and monitor commerce, industry and human services. It is generally agreed that our governmental agencies have not been entirely effective. Some of the people involved make errors in judgment and, in some cases, join in criminal activity for profit or prestige. While we are alarmed by these failures of our governmental regulatory agencies, the system is still a useful and necessary one.

At the state level there is ordinarily a major governmental agency whose director is responsible for the development and operation of public services for mentally retarded individuals. This primary agency may be a separate authority for mental retardation services although, in many states, it is part of an umbrella agency which is also responsible for mental health services and, in some cases, for welfare programs. In addition, there are other state and local agencies involved in the certification and licensure of residential programs.

When the federal Medicaid Program (Title XIX of the Social Security Act) began to fund large numbers of residential services, the questions of accountability became a public issue of heated debate. These new programs were called Intermediate Care Facilities (ICFs), with a special set of regulations for mental retardation services under a separate category of ICFs. These mental retardation services are commonly known as ICF/MRs. Since the Intermediate Care Facilities were designed as medical programs under law, certification became a responsibility of the state's health agency which normally licensed nursing homes. The surveyors who suddenly became responsible for determining whether a specific program met the federal regulations were often poorly prepared for the new responsibility. Surveyors were knowledgeable about nursing homes but knew little about mental retardation. There were incidents of confused and sometimes fraudulent certification, but most surveyors agreed with the demands of advocacy groups, such as the ARC, that training programs and consultation were needed to assure that the ICF/MRs were properly evaluated. There is, however, an ongoing need to monitor these facilities and, where necessary, bring infractions to the attention of certification agencies or perhaps to the state's attorney general. Since the ICF/MR uses federal money, the regional federal Offices of Long Term Care are also responsible for monitoring compliance with federal regulations and the effect of those regulations on the provision of services. If a breakdown in effectiveness occurs at either local, state or federal level, it is the advocate's responsibility to point it out.

The Advocacy Role and the Law

The concept of monitoring services by advocacy groups or by individuals is as old as recorded history, but it has taken on some new qualities during the past several years. The politics of confrontation reached a peak of fervor in the late 1960s, and many of the confrontation methods were incorporated into the activities of advocacy groups. The nation as a whole became caught up in the use of litigation as a preferred strategy for resolving grievances of every imaginable sort. Never in history have so many people sued each other in courts of law. Legal court battles involving human services of all types became common as consumer advocacy efforts gained popularity and courts agreed to hear more class action suits.

It can be effectively argued that litigation was the only option left to advocates who had tried unsuccessfully with other methods to bring about improvements in the way services were provided. Administrators and government officials had seemingly become immune to pleas and demands for better services, or else they were unable to make the necessary program changes because they either lacked the money or the authority to do so. By taking their grievances to the justice system, advocates were then able to gain legal clarification of what we should expect from service providers. Court decisions also enunciated and clarified the citizenship rights of mentally retarded persons.

In 1975 Rutherford Turnbull, III, reviewed the issue of legal accountability as it relates to professionals. He noted that within the rather complex judicial conclusions regarding mentally retarded and handicapped people, there are two major themes: "First, human and constitutional rights are not divisible and may not be legally parcelled out according to the mental, emotional, or physical attributes of a person; and, second, the unequal person is entitled to equal treatment under the law." Turnbull also pointed out that "behind these judicial responses lies the engrained belief of society, enforced at law, that persons should be answerable to each other for what they do to each other."

Legal approaches appeared to be necessary because of the political nature of state-level service administrators. Even those administrators who expressed great interest and eagerness to change the way services were being provided found themselves helpless to implement those changes because of political pressures to maintain the status quo. Many politically powerful industries had direct interests in maintaining the large multipurpose institutions and feared financial losses if the traditional system was altered. Businesses which contracted with the state to supply services and goods to the institutions brought their considerable political and financial influence to bear on legislators and other government officials. Labor unions, in some cases, became highly resistant to any changes which might result in loss of jobs for their members.

While the economic interests of these industries and labor unions are understandable, advocates charged that economic interests were being promoted at the expense of those vulnerable individuals for whom the services were supposed to be designed. Such pressures tended to block efforts by residential services administrators to develop new programs outside the traditional institutional structure. Legal confrontation was able to cut through many political barriers. It created bitterness, however, among many professionals and parents who were caught in the middle of a struggle they did not fully understand. Middle management personnel, who were often sympathetic to the need for change, found themselves unable to bring about the changes ordered by courts. Their budgets simply did not include funds for transferring services into a community-based system. As a result, managers became scapegoats for both sides in what amounted to a money-war between politicians and advocates. Middle management personnel were understandably bitter about legal confrontations in particular and the whole concept of monitoring in general.

Obviously, the legal process of calling an agency or individual to accountability before a court of law is quite a complex undertaking. There are references at the end of this chapter which offer practical discussions of the legal process and its underlying theories.

Monitoring

Considering the number of regulatory agencies whose legislated purpose is to monitor and regulate services, one might ask, "Why should parents or other advocates need to monitor these services at all?" It is a realistic question. Advocates need to monitor programs because, quite bluntly, history has shown us that we cannot depend upon the providers of services to always act in the best interests of their clients. We should hasten to note, however, that most service providers are sincere and highly motivated people who make every effort to act in their client's best interest. These providers welcome the advocate's concern and encourage the monitoring process. Even the most highly motivated administrator knows that his program needs the advocate's concerned involvement. He and his staff can and do make errors in judgment occasionally. Also, the pressures and demands of service management can overshadow individual student needs in such a way that staff may be unaware of program flaws. The advocate's vigilance and willingness to point out these problems contribute to program viability and to staff effectiveness.

Often there is confusion over the difference between the monitoring process of volunteer advocates and the monitoring process of accreditation, certification and licensure. Advocacy groups monitor programs and facilities on a regular ongoing basis using basic criteria which ordinarily require only general knowledge of mental retardation and program technology. On the other hand, a more formal process of accreditation or certification is conducted at periodic intervals by trained professionals using highly specific criteria for health, safety and program quality.

It is, of course, helpful for the advocacy group to know and understand the more formal criteria of accreditation standards, Medicaid regulations and state-adopted standards for licensure and certification. Each state has its own set of standards governing residential services, and these standards or regulations are available from the state agency responsible for mental retardation services. The Title XIX Medicaid (ICF/MR) regulations are available from either the regional federal Office of Long Term Care or from the Superintendent of Documents in Washington, D.C. The accreditation standards are available from the Accreditation Council for Services for Mentally Retarded and Other Developmentally Disabled Persons.

The advocacy group which plans to monitor residential services will consider at least four aspects of a particular program:

- Quality of service
- Protection of human and legal rights
- Adequacy and appropriateness of supervision
- Appropriateness of back-up and supportive services

Because of the potential for abuse in handling a student's money in a residential program, many advocacy groups add a fifth area for monitoring — financial accountability. Unfortunately, there continue to be examples of unscrupulous group home and nursing home administrators who collect and keep the client's Social Security benefits, salary checks or money from home. A recent investigation in Texas, for example, revealed that the operator of a small halfway house had illegally appropriated some $14,000 of her clients' money for her own personal use.

There have been numerous exposés of nursing home operators who not only victimized their clients financially but also subjected them to regular physical and mental abuse. Mentally retarded individuals, like the chronically ill and elderly, are most often unable to protect themselves from such abuse or to speak out on their own behalf. If we, as healthy and mentally alert citizens, do not accept our responsibilities to monitor such facilities and programs, we participate, by default, in the abuse.

Investigations in several states have led to shocking discoveries of squalid and inhumane conditions within nursing homes. For the most part, these unfortunate situations had been going on for rather long periods of time before they finally came to the general public's attention. A shocked and bitter public wanted to know why their governmental agencies, who were presumably responsible for checking these homes and granting them licenses to operate, had failed to prevent such atrocities. In many cases it was discovered that the responsible state agency had granted licenses to homes which were in flagrant violation of both state and federal regulations. In many cases the state agency claimed that it had no authority to monitor the way services were actually delivered — their authority appeared to cover only the physical facility — they monitored only such things as general fire safety, sanitation, medication procedures, numbers of patients per room, width of doors and hallways, kitchen equipment and other non-programmatic areas.

Nursing home scandals became a nationwide problem primarily because few agencies seemed able or willing to control the abuses. There are unresolved charges that political influence is a major factor in our failure to regulate the massive nursing home industry where many retarded citizens reside. When a flood of federal dollars became available for nursing home care, these facilities seemed too many to become good financial investments. It is, perhaps, this idea of profiteering on helpless, elderly or mentally and physically handicapped people which makes so many advocates suspicious of nursing home programs. Unfortunately, the nursing home industry seems to have difficulty controlling itself through its own organization. At this point in time, there continues to be great resistance from many nursing home operators to allowing advocates inside their facilities to monitor the service and the programs. So long as these facilities resist monitoring efforts by advocacy groups, they will remain suspect and the admission of mentally retarded people to such facilities will be opposed by advocates. The same posture applies equally to any public or private facility, whether it calls itself a nursing home, group home or board and care home. The seclusion of handicapped and disabled citizens in places which deny access to their advocates is totally unacceptable.

The Process

The Association for Retarded Citizens, through its national position statements and its volunteer committee structure, has repeatedly stated that monitoring procedures can and should be friendly and non-threatening. If, however, those responsible for services seem unwilling or unable to correct program deficiencies and meet minimum standards, then more stringent methods are necessary. Legal charges can be made against those who fail in their contract to provide appropriate services. The legal route is often a lengthy and expensive process and certainly should be avoided whenever possible. Yet, it is always an available option when all else fails.

The process of monitoring is too often viewed, however, as a hostile process which draws offensive and defensive lines of conflict. Hostility, as a behavior, is usually the result of fears and insecurities on both sides of the issue. Parents, for example, tend to become hostile when they are frustrated in their efforts to improve opportunities and services for their son or daughter. Most parents feel helpless to improve programs because they have little practical knowledge of how such improvements can be accomplished. Professionals may become hostile because they feel that their competence as professionals is being questioned, and they, in turn, are helpless to bring about improvements without the necessary administrative and budget support. Also, top administrative officials tend to react with hostility to criticisms from advocates because they feel the advocates make the problems sound like simple yes/no issues without an appreciation of the complex political, legal and financial problems associated with major changes in the service system.

In spite of these varied human responses, the monitoring process can be a mutually rewarding activity if both the monitor and the monitored choose to make it so. The volunteer monitor's primary role is not one of fault-finding. Monitoring involves finding out how services and programs actually work. Monitoring focuses upon what happens to the individual students in a residential facility, recognizing program successes as well as failures. The monitor is a collector of information about how a particular service benefits each of its clients. Constructive monitoring recognizes and evaluates problems or barriers to program success and searches for the real source of those problems.

A frequent but puzzling approach to problem solving among parents and other advocates is the acceptance of excuses as though they were logical justifications. For example, during an ARC local unit committee visit to a residential facility, committee members noticed that certain students were in straitjacket-type restraints. The committee was told by program managers that it was indeed an unfortunate situation, but necessary, because there were not enough staff to supervise these two hyperactive residents, and there were no funds to hire additional staff. Responsibility for an unhealthy situation was thus shifted to the "lack of funds" category. The committee was expected to accept this response as justification for keeping two young people restrained and isolated from any learning opportunities. Unfortunately, many monitoring committees are thus led to accept situations which are clearly unacceptable.

While it may be true that staff shortages contribute to unhealthy and inhumane situations and that funds are not available for more staff, those reasons do not make the situation acceptable. However, it is pointless to berate staff members for a

situation they are helpless to control. It is far better to meet with those staff members and try to solve the problem by exploring the following questions as a group:

1. What is the basic problem?

In the example of residents being left in physical restraints, the real problem is the fact that two individuals are being deprived of opportunities to move about and participate in some needed learning experiences. Factors which contribute to the problem are (a) the residents are unable to control their own behaviors and consequently endanger themselves and others; (b) current available staff members are unable to control the residents' behavior sufficiently to reduce the dangers associated with allowing them to go unrestrained; and (c) additional staff are unavailable.

2. What are the ways in which the problem might be solved?

- What, exactly, are the behaviors which require restraints?
- What techniques are available to modify those unacceptable behaviors and teach acceptable behaviors?
- Are there different programs, already available, which could be used to reduce or eliminate the problem?
- Why are staff members unable to control these particular resident behaviors? Is it a question of not knowing what to do, or not having the time and opportunity to apply known skills?
- Can program schedules be rearranged to provide different staff assignments which would alleviate the problem?
- Is outside expert consultation needed to help define and solve the problem?
- Do the staff need some type of inservice training to help them understand and deal effectively with the problem by developing new skills?
- What administrative decisions determine the number and qualifications of staff?
- If additional funds are determined to be essential for resolution of the problem, what strategies are suitable to secure those needed funds?

Monitoring can be done on both an individual and group basis. In fact, each time a family member or personal advocate visits the relative or friend who lives in some residential program, they have an opportunity and obligation to monitor the services that person is receiving. The entire sequence of questions and observations relative to effective monitoring could probably not be completed during one visit, but over time, each of the major areas should be covered. The sensitive advocate will concern himself with the welfare of all residents in the program, knowing that the welfare of a relative or friend is closely tied to the welfare of every other person in the residential program.

Although individual monitoring is of paramount importance, it is the organizational or team monitoring process which is essential to the long-term success of community-based residential service systems.

When mentally retarded individuals are living in small groups dispersed throughout a community, it is especially important that a regular ongoing monitoring program be established. Volunteers must be recruited and prepared to serve as monitors. If community-based residential programs are to fulfill the promise they hold for improved services, parents and society as a whole must have some assurance that students of these programs will always have advocates concerned about their health and welfare. Organizational advocacy promises greater durability over time and thus provides a greater sense of security for families who may not always be around to serve as advocates for their own relatives.

Group, or team monitoring may involve volunteers from different community groups, but these efforts should be coordinated by one single advocacy organization. For example, the local unit of the Association for Retarded Citizens may establish a special committee to coordinate monitoring of community services. The process may also be coordinated through the ARC's Citizen Advocacy program or its Residential Services Committee. A rather wide range of citizens from other civic, social and service organizations may participate in the effort. Many people who are not members of the ARC are often interested in helping with the monitoring process and are willing to commit themselves to the program for a couple of years or more. It is imperative, however, that all volunteers go through a structured orientation and training sequence. Every person involved in the monitoring process must have a clear understanding of his role and its limitations.

Most monitoring approaches involve some type of checklist and report form to guide them in covering each aspect of the service and in maintaining permanent records of their visits. There are very few checklists available and, therefore, the ARC usually develops its own, based on state-mandated standards, federal regulations and accreditation standards. Also, because of differences in the types of community-based residential programs, no single checklist is apt to be appropriate for every type of service. It has been suggested by some monitoring groups that a single checklist be developed and individual questions coded for use in each type of service. For example, the large multipurpose facility may require the most extensive set of questions, while only specific questions in each area would be coded for use in small group homes and another sequence of questions coded for semi-independent apartment living.

In 1972 the Association for Retarded Citizens, National Headquarters, published a series of four booklets and a checklist for observing and monitoring institutional programs. The series, titled **Residential Programming for Mentally Retarded Persons,** is available from national headquarters. The Pennsylvania unit of the Association for Retarded Citizens has also developed one of the more detailed guides for volunteer monitoring of public residential facilities. The Pennsylvania unit's Residential Services Committee regularly sends teams to observe and report on the state's public residential program. Monitoring guidelines, specific to smaller community residential facilities, are currently being developed by a variety of groups. A major effort has been made by the Center for Development of Community Alternative Service Systems in Omaha, Nebraska. This approach involves a detailed set of questions along with discussions and examples of each issue.

It should also be noted that most team members of the ARC in Pennsylvania program, as well as those in other states, have been additionally prepared for their task by participating in workshops which taught the use of the PASS (Program Analysis of Service Systems) method developed by Wolf Wolfensberger and Linda Glenn. The PASS method permits observers to evaluate the degree to which a facility meets criteria for normalized life styles.

Questions for Monitoring

A model checklist, adapted from one developed by Cassandra Smart of the Dallas County Mental Health & Mental Retardation Center, has been included in this chapter to help the advocacy group assess its own needs for such a checklist.

The following questionnaire is intended only as an example of a guide for assessing or monitoring a community-based residential program. Most of the questions are designed to require "Yes" and "No" answers.

It is expected that completion of a questionnaire such as this one will require direct observation and interviews with direct-care staff and will take at least two hours to complete. It is intended that the questionnaire will provide parents and advocates with a structure for evaluating the facility and program as it relates to the needs of their family member or friend. There will also be additional questions or concerns wherein parents and advocates will need to address issues as they relate to specific individual needs (e.g., medical coverage and support services). An evaluation of the completed questionnaire should be done by a committee or team of the advocacy organization.

Here are the basic steps in "common sense monitoring":

- Before the first visit to the facility, review available documents regarding purpose, philosophy, budget, staff, residents, etc.
- Schedule a visit and directly observe activity at the facility and interaction between staff and students.
- Review individual resident records.
- Compare records with your observations.
- Interview direct care staff, professionals, administrators, residents and their parents.
- Complete the monitor's questionnaire independently.
- Compare your questionnaire with those of the other monitors.
- Present your findings and discuss them with the committee.
- Develop recommendations.
- Establish action steps and desired time frame.
- Follow through!

Yes No

I. Facility

A. Location

1. Is the residence in a typical residential area where the average person would feel comfortable? ________ ________

2. Are stores such as a grocery store, a discount store, etc. within walking distance of the residence? ________ ________

3. Are recreational areas such as a park, a fast-food restaurant, a theatre, a bowling center or other recreational site either within walking distance or easily accessible either by public transportation or by transportation provided by the program? ________ ________

B. Quality of Facility

1. Does the residence have a homelike atmosphere? Does it fit the "style" of the neighborhood? ________ ________

2. Is the facility in good repair? If not, what is wrong? ________________ ________ ________

____

____

____

3. Is the facility clean? If not, what is wrong? ________________ ________ ________

____

____

Are there plans for doing needed clean-up? ________ ________

4. Is someone responsible for maintenance of the interior of the facility? ________ ________

Who is responsible? ____

5. Is someone responsible for the maintenance of the exterior of the facility? ________ ________

Who is responsible? ____

6. Is the facility well-ventilated? (That is, are there as many windows which are operational as you feel are needed in the facility?) ________ ________

Is there air conditioning which you feel is sufficient for the facility and the climate in which the facility is located? ________ ________

Is there a heating system which you feel is sufficient for the facility and the climate in which it is located? ________ ________

(In short, would you be comfortable living there?) ________ ________

If not, what is wrong with the ventilation? ________________________

____

____

____

____

C. Safety

1. Are there fire alarms? ________ ________

NOTE: It is recommended that facilities should be equipped with smoke detectors which are battery operated. Detectors should be located so that they can detect fire in all parts of the house. If you are in doubt as to whether there is a sufficient number of smoke detectors and whether they are located properly, ask the staff to explain. If you are not satisfied with their response, note the brand name of the smoke detectors and contact one of the following with your questions: a) the manufacturer; b) the distributor; c) your local fire department; or d) your local fire marshal or inspector.

2. Is there a posted fire/emergency escape plan? ________ ________

3. Are fire escapes available in both single and multi-story facilities? ________ ________

NOTE: Fire escapes may be windows, balconies with stairs to the ground, doors, etc.

4. Are the fire escapes in good repair? ________ ________

5. When necessary for resident safety, are dangerous substances (e.g., bleach, cleaners, poisons and insecticides) securely stored? ________ ________

Where are they stored? ____

____

	Yes	No
D. Rooms		
1. Living Area:		
a. Is there an area set aside for social or recreational activities? (This area might be a living room or den.)	______	______
b. Is the living area homelike (e.g., are the furnishings such that you feel that the residents find them functional, homelike and comfortable)?	______	______
2. Dining Area:		
a. Is there a dining area?	______	______
b. If the residents wish to do so, is the dining area sufficiently large so that everyone can eat at one time (e.g., are there enough chairs, tables, space)?	______	______
c. Is the dining area homelike (e.g., are the furnishings comfortable, attractive, etc.)?	______	______
3. Kitchen and Laundry:		
a. Do the residents use the kitchen?	______	______
NOTE: It is recommended that the kitchen be used in teaching residents to prepare meals, to prepare snacks, to learn menu planning, etc.		
b. Are kitchen appliances safe and in good repair (i.e., do you feel residents are safe when working in the kitchen)?	______	______
c. Are laundry facilities available in the residence?	______	______
If not, is there a laundromat within walking distance?	______	______
4. Bedroom and Bathroom:		
a. Are there no more than one or two residents per bedroom?	______	______
b. If not, does each resident have at least 80 square feet of bedroom space?	______	______
How many residents are there in each bedroom? ____________		
Do the bathroom facilities provide for privacy?	______	______
c. Are the bathrooms accessible to handicapped residents?	______	______
d. Does each resident have adequate storage space in the bathroom?	______	______
e. Are the bathrooms clean and in good repair?	______	______
E. Physical Barriers		
1. Is the facility barrier free?	______	______
2. If not, are there provisions made for placement of physically handicapped individuals?	______	______

Where are these facilities and what are their names? ____________

II. Program

A. Goal

	Yes	No
1. Can staff members state the goal of the program?	______	______

What is it? ____________

B. Individual Program Plan

	Yes	No
1. Is there a comprehensive evaluation prior to or upon admission? (The evaluation should cover physical, emotional, social and cognitive factors.)	______	______

Who does the evaluation(s)? ____________

	Yes	No
2. Is there an individual program plan for each resident?	______	______
3. Is there full participation in the individual program plan process?	______	______

NOTE: The process should include the resident, appropriate direct care staff, parents, especially if the resident is a child, and appropriate support service staff.

	Yes	No
4. Does the individual program plan include:		
a. Established priorities for meeting the resident's needs?	______	______
NOTE: Priorities should be determined with the resident's input.		
b. Specific behavioral objectives?	______	______
NOTE: There should be a time frame within which the objective is to be achieved.		
c. Methods and strategies to be used in training?	______	______
d. Persons responsible for conducting the training?	______	______
5. Is there a regular review (at least every six months) of the individual program plan?	______	______
6. Is the individual program plan available to the resident upon request?	______	______
C. Activities		
1. Are there day activities for residents?	______	______
NOTE: Day activities may include a school, a developmental center, a sheltered workshop, a work training center or competitive employment.		
2. Does the resident have options in the kinds of activities in which he may participate?	______	______
3. Are community resources (e.g., recreational facilities, schools and churches) used?	______	______
4. Are there activity schedules?	______	______
If so, are residents involved in structuring their own schedules?	______	______
5. Are there options for the use of free time?	______	______
What are some of the optional activities in which a resident might engage? ______________________________ ______________________________ ______________________________		
6. Do residents have an opportunity to participate in a vocational habilitation program (e.g., sheltered workshop, work training program; or for children, developmental center, day school or other educational program)?	______	______
Is placement in a vocational habilitation program reflected in the IPP?	______	______
7. Do residents have daily interactions with individuals from outside the residential unit?	______	______
What type of interaction (vocational program, recreation, etc.) and how many hours per day? ______________________ ______________________________ ______________________________		
8. Are residents responsible for duties in the residence?	______	______
(Residents should be assigned responsibilities in the residence and the responsibilities should be commensurate with their interests, abilities and developmental plans in order to enhance feelings of self-respect and to become trained in skills of everyday living.)		
Duties might include cooking, cleaning, shopping, etc.		
9. Are self-feeding skills, table manners and nutrition taught as needed?	______	______
Who teaches these skills? ______________________		
When are they taught? ______________________		
10. If needed, are feeding skills taught at mealtimes?	______	______
Who teaches these skills? ______________________		
11. Do residents have an adequate supply of neat, clean, fashionable, seasonable and age appropriate clothing?	______	______
12. Are residents trained in self-dressing skills if needed?	______	______
When are they taught? ______________________		
Who teaches these skills? ______________________		

Yes No

13. Are residents trained in selecting their daily clothing? ______ ______

When are they taught? ______

Who teaches these skills? ______

14. Are residents trained in shopping for their own clothing? ______ ______

When are they taught? ______

Who teaches these skills? ______

Who picks out the clothes? ______

15. Are residents trained in health, hygiene and grooming practices, including bathing, brushing their teeth, shampooing, combing and brushing hair, shaving and caring for toenails and fingernails? ______ ______

When are they taught? ______

Who teaches these skills? ______

16. Are female residents helped to attain maximum independence in caring for their menstrual needs? ______ ______

When are they taught? ______

Who teaches these skills? ______

17. Is a toilet training program provided to residents who need it? ______ ______

Who teaches this? ______

18. Are teaching materials for all of the above mentioned activities available? ______ ______

Where are the materials kept? ______

______

D. Diet

1. Is there a planned, nutritionally adequate diet for all residents? ______ ______

2. Is there someone responsible for the nutritional adequacy of the meals? ______ ______

Who? ______

3. In your opinion, is the food good?
(This may be determined by observing a meal, talking to residents, etc.) ______ ______

4. Do the residents participate in the selection of foods and are there options to choose from at mealtime? ______ ______

E. Money

1. Are residents allowed to have possession and use of money? ______ ______

2. Are there opportunities for residents to earn money? ______ ______

What are the opportunities? ______

______

______

3. Is there appropriate provision made for the protection of a resident's personal funds? ______ ______

What kind of provision is made? ______

______

4. Is the resident offered individualized counseling or training on how to maintain his own funds? ______ ______

When are they taught? ______

______

Who teaches these skills? ______

______

F. Transportation

1. Is transportation available? ______ ______

a. Is public transportation available? ______ ______

What kind? ______

	Yes	No
b. When public transportation is not available or when residents cannot use public transportation, is transportation provided?	______	______

How is transportation provided? ______________________________

____

2. Is transportation available on weekends and in the evenings?	______	______

What kind? ______________________________

3. If public transportation is available, are residents trained in its use?	______	______

When are they taught? ______________________________

Who teaches these skills? ______________________________

G. Medication

1. If a resident takes medication regularly, how often is the medication evaluated?

____

____

2. Is a staff member designated to monitor a resident's medication administration?	______	______
3. Are medications stored safely?	______	______

Where? ______________________________

4. Are observations of a resident's response to medication recorded?	______	______

Where is the response recorded? ______________________________

____

5. Are residents taught the skills needed to be self-medicating?	______	______

Who teaches these skills? ______________________________

____

H. Staff

1. In your opinion, is there an adequate number of staff engaged in direct services?	______	______

	morning	afternoon	evening/night
Number of direct service staff:	______	______	____/____
Number of residents:	______	______	____/____

2. Are there adequate support services? (Support services include medical, emergency medical, dental, occupational and physical therapy, speech and hearing, visual, psychological.)	______	______

a. Support services available to all residents, as needed: ______________

____

____

____

____

b. Who provides the support services? (***Provider*** might be MH/MR Center, private source, public source, hospital, community resource, etc.)

____

____

____

____

____

III. Personal Rights

A. Policies and Procedures

1. Are residents involved in the formulation of policies and procedures?	______	______
2. Are residents specifically involved in formulation of procedures relating to discipline?	______	______

	Yes	No
What are the policies relating to discipline? ______________________		

____

____

____

____

____

B. Visits

1. Are visits permitted at reasonable hours?	______	______
What are the visiting hours, if any? ______________________		
2. When people do visit, are steps taken to consider the sensitivities and privacy of the residents?	______	______
3. Are visitors encouraged to realize that they are visiting someone's private home?	______	______

C. Personal Possessions

1. Are residents permitted to have personal possessions? (Personal possessions include decorative items, televisions, radio, sports equipment, etc.)	______	______

D. Telephone Use and Mail Privileges

1. Do residents have access to a telephone and mail?	______	______
Are there any restrictions which may be placed either on telephone use or mail?	______	______

If so, what are they? ______________________

____

____

____

____

E. Religious Services

1. Are residents given the option of attending religious services?	______	______

2. How do residents get to and from religious services? ______________________

____

F. Residents Helping Other Residents

1. Are residents involved in the care (feeding, clothing, bathing), training or supervision of other residents?	______	______
If so, are the residents rendering services:		
a. Specifically trained in these necessary skills?	______	______
Who does the training? ______________________		
b. Taught to exercise humane judgment in these activities?	______	______
c. Provided adequate supervision?	______	______
Who supervises? ______________________		
d. Paid for their work?	______	______
How much are they paid? ______________________		

In what ways are residents involved in the care of other residents?

____

____

____

____

G. Reference to Residents

1. How do staff refer to the residents (e.g., "clients," "residents," "trainees," "students," "pupils," "patrons," "patients," "inmates," "retardates," "kids," or "children")? ______________________

____

2. How would you describe the relationship between staff and residents (e.g., adult to adult, parent to child, etc.)? ______________________

____

____

Yes No

H. Physical Restraints

1. If physical restraint is used, is it used only as an integral part of an individual program plan that is designed by an interdisciplinary team to lead to a less restrictive way of behavior management and ultimately to the elimination of the behavior for which the restraint is applied?

a. If restraints are used, what types are used? ____________________

b. For how long are restraints applied? ____________________

c. By whom are restraints applied? ____________________

d. How is the use of restraints recorded? ____________________

e. Under what circumstances are restraints applied? ____________________

2. Are seclusion rooms used? ________ ________

Who is responsible for placing residents in seclusion? ____________________

Are residents in seclusion monitored? ________ ________

I. Voter Registration

1. Are residents registered to vote? ________ ________

2. Did residents vote in the last election? ________ ________

IV. Issues Upon Which to Gather Information

A. Discipline

1. What kinds of disciplinary measures are used? ____________________

2. When are disciplinary measures implemented? ____________________

B. Rules and Regulations

1. What are some of the rules and regulations which residents are required to follow? ____________________

2. If it is available, obtain a copy of the rules and regulations which residents are required to follow. ________ ________

C. Transfer, Discharge and Dismissal on the Basis of Misconduct

1. Transfer:

a. Can a resident be transferred to another program or home because of misconduct? ________ ________

Yes No

b. If the answer to the above question is "yes":

(1) What are the types of misconduct which result in transfer? ______

(2) To what program(s) would the resident be transferred? ______

(3) Who decides on transfer? ______

2. Discharge and/or Dismissal:

a. Can a resident be discharged and/or dismissed because of misconduct? ______ ______

b. If the answer to the above question is "yes":

(1) What are the types of misconduct which would result in discharge and/or dismissal? ______

(2) What alternate placement(s) would be provided for the dismissal or discharge of resident? ______

D. Costs

1. What is the average cost per resident per day for daily living expenses (room and board)? ______

2. What is the average cost per resident per day for training? ______

3. What is the average cost per resident per month for support services? ______

4. Will the resident or family be expected to pay all or part of his program cost? ______ ______

5. If the answer to the above question is "yes":

a. When will the resident be expected to begin payment (immediately upon entry, after three months, etc.)? ______

b. How much will the resident be expected to pay per month? ______

V. General Impression and Summary of Program

______

Report prepared by: ______

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8

RESOURCES

The next best thing to knowing something is knowing where to find it.

THE ADULT PERFORMANCE LEVEL PROGRAM
Date: 1978
Source: APL Department
The American College Testing Program
P.O. Box 168
Iowa City, Iowa 52240

This instrument is an objective-based assessment program which measures the life skills proficiency of young and mature adults. The program consists of six instruments — a general survey and five in-depth content area measures — useful for curriculum planning, program evaluation and the identification of strengths and weaknesses of mildly retarded adults.

ANALYZING COSTS IN A RESIDENTIAL FACILITY FOR CHILDREN
Date: 1969
Source: Child Welfare League of America
67 Irving Place
New York, New York 10003

The manual is organized into five major sections:
- Organizing for costs analysis
- Expenses are analyzed and allocated
- Parent organization expenses and institution services
- Donated goods and expenses associated with donations
- Preparing cost analysis report

CLIENT RECORD SYSTEM: FACILITIES FOR THE MENTALLY RETARDED: A TRAINING GUIDE
Date: 1977
Source: Ames Medical Records Systems
32 Cobble Hill Road
Somerville, Massachusetts 02143

A records system originally prepared for the Massachusetts Department of Health. The training guide provides detailed descriptions of a structure for client records.

A CONSUMERS MONITORING TOOL
Date: 1977
Source: Center for Development of Community Alternative Service Systems
Box 118
4300 Emile Street
Omaha, Nebraska 68131

A guide for assisting disabled persons, their relatives and their advocates in determining the appropriateness and suitability of a residential service. Some of the areas discussed are:
- Assessment
- Individual program planning
- Management
- Health and safety
- Legal rights
- Educational and vocational services

THE DIRECTORY FOR EXCEPTIONAL CHILDREN: A LISTING OF EDUCATIONAL AND TRAINING FACILITIES. — (Eighth edition)
Date: 1978
Source: Porter Sargent Publishers
11 Beacon Street
Boston, Massachusetts 02108

The latest edition lists over 3,000 schools, clinics and treatment centers for exceptional children. Both public and private facilities are listed, including boarding schools, out-patient clinics and residential and day facilities. A comprehensive listing of organizations in the U.S. and Canada directly or indirectly concerned with the welfare of exceptional children is included in this edition.

ESTABLISHING AND OPERATING COMMUNITY LIVING CENTERS FOR MENTALLY RETARDED ADULTS

Author: J.E. Bridges
Date: Undated
Source: The Marbridge Foundation
P.O. Box 250
Manchaca, Texas 78652

Based on actual successful experience in operations of successful community living centers for mentally retarded young adults, this booklet is intended as a guide to prospective groups who plan to establish a living center for mentally retarded individuals in their community.

FACTORS TO CONSIDER IN SELECTING A TRAINING HOSTEL OR GROUP HOME

Author: John W. Fanning
Date: 1974
Source: Mental Health Services of the Roanoke Valley
Suite 500
Carlton Terrace Building
Roanoke, Virginia 24016

A small, easy to use, checklist of questions relating to initial selection or monitoring of small group living programs. The questions are divided into the following areas:

- House and neighborhood
- Accessibility and convenience
- House structure and interior
- Outdoor area
- Safety codes and restrictions
- Special observations

FAMILY CARE TRAINING HOMES: MANUAL OF PROCEDURES

Date: 1974
Source: Macomb-Oakland Regional Center
16200 Nineteen Mile Road
Mt. Clemens, Michigan 48043

Included in this manual are guidelines, procedures, descriptive material and forms (policy letters, checklists, evaluations, etc.), inservice training schedules and inservice training objectives for family care training homes.

HABILITATION OF SEVERELY AND PROFOUNDLY RETARDED ADULTS: REPORTS FROM A SPECIALIZED TRAINING PROGRAM

Editor: G. Thomas Bellamy
Date: 1976
Source: Rehabilitation, Research and Training Center
in Mental Retardation
Center on Human Development
University of Oregon
Eugene, Oregon 97403

Compiled to facilitate rapid, informal dissemination of research and demonstration activities in the Specialized Training Program at the University of Oregon. Research in the Specialized Training Program has been designed to provide practical information which may help other community agencies attempting to meet these needs.

THE INDIVIDUAL PROGRAM AND ASSESSMENT GUIDE

Date: Undated
Source: Developmental Services, Inc.
Residential Services
P.O. Box 1023
Columbus, Indiana 47201

This guide is an instrument to provide assessment and programming for mentally retarded adults in a residential training program. The guide provides a basis for developing a prescriptive training program based on the specific needs of each adult. The manual is divided into the following skill areas: laundry and clothing care; communication skills; socialization skills; grooming and personal hygiene; banking and money management; marketing skills; culinary skills and meal planning; table etiquette; housekeeping skills; kitchen skills; daily living skills; employment needs; leisure time skills and activities; and community mobility skills.

LET OUR CHILDREN GO: AN ORGANIZING MANUAL FOR ADVOCATES AND PARENTS

Author: Douglas Biklen
Date: 1974
Source: Center on Human Policy
P.O. Box 127
University Station
Syracuse, New York 13210

Designed for parents of children with disabilities, this publication summarizes the thoughts of parents and advocates who have struggled for resources to meet the needs of handicapped children. The role of advocacy is emphasized to ensure that the rights of handicapped people are upheld.

MARKING TIME: TUTOR TEXT FOR TEACHING CALENDAR SKILLS

Date: 1978
Source: Elwyn Educational Materials Center
Elwyn Institute
Elwyn, Pennsylvania 19063

Designed as a programmed learning text which allows each student to work at his or her own speed with minimal teacher assistance. Topics covered include the purpose and use of the calendar, the concept of passage of time, seasons and holidays. Exercises in identifying, locating and writing dates are presented in detail.

OBSERVING IN INSTITUTIONS (Notes from the Center, No. 2)

Author: Robert Bogdan
Date: 1974
Source: Center on Human Policy
P.O. Box 127
University Station
Syracuse, New York 13210

A series of questions intended to serve as a guide for observing the nature of life in a variety of institutions (i.e., state mental health facilities and state schools). Questions focus on policies, practices, programs and conditions of institutional life.

OPENING CLOSED DOORS: THE DEINSTITUTIONALIZATION OF DISABLED INDIVIDUALS

Author: David Braddock
Date: 1977
Source: Council for Exceptional Children
1920 Association Drive
Reston, Virginia 22091

A concise and unified textbook-like survey of current trends and issues pertaining to institutionalization in America. References, annotated bibliography and supporting appendices are included.

PERSONAL ADJUSTMENT TRAINING (3 volumes)

Date: 1975
Source: Elwyn Educational Materials Center
Elwyn Institute
Elwyn, Pennsylvania 19063

A structured group counseling curriculum designed to ameliorate those social deficiencies associated with institutionalization and cognitive deficits. Volume II includes counseling programs to teach assertive responses and deals with patterns of compliance, withdrawal, passivity, etc. Volume III deals with helping persons recognize their own inappropriate behaviors and motivating them for change.

REINTEGRATING MENTALLY RETARDED PEOPLE INTO THE COMMUNITY: AN ANNOTATED BIBLIOGRAPHY OF PRINT AND AUDIOVISUAL INFORMATION AND TRAINING MATERIALS

Date: Undated
Source: Council for Exceptional Children
1920 Association Drive
Reston, Virginia 22091

This bibliography contains annotations on journal articles, books, booklets, project reports, and monographs, films and slides, covering the years 1962 through 1975. It was compiled from mail surveys, computer searches of national information systems, library searches and a telephone survey of developmental disabilities consultants.

STANDARDS FOR SERVICES FOR DEVELOPMENTALLY DISABLED INDIVIDUALS
Date: 1978
Source: Accreditation Council for Services for Mentally Retarded and Other Developmentally
Disabled Persons
875 North Michigan Avenue
Suite 2201
Chicago, Illinois 60611

Accreditation Standards are designed for application to all agencies servicing developmentally disabled individuals, and are intended to be used in assessing an agency's compliance with applicable standards. They are applied selectively, depending upon their pertinence to a given agency's operation.

TAKE STEPS TO LOOK AND LEARN: A GUIDELINE FOR OBSERVING RESIDENTIAL FACILITIES
Author: PARC Residential Services Committee
Date: 1978
Source: Pennsylvania Association for Retarded Citizens
1500 North Second Street
Harrisburg, Pennsylvania 17102

A detailed guideline to prepare volunteer advocates for monitoring public residential facilities. Recommendations are given for the observation process and a questionnaire provided to structure team observations.

A TRANSITIONAL PROGRAM FOR INSTITUTIONALIZED ADULT RETARDED
Date: 1975
Source: Elwyn Educational Materials Center
Elwyn Institute
Elwyn, Pennsylvania 19063

Described as a comprehensive institutional rehabilitation project. Topics include the setting; program and research methodology; the techniques of assessment with individuals; a statistical report on community adjustment of graduates; and correlative data relating demographic information, psychometric data and measures of institutional adjustment to selected criteria of post-institutional functioning.

PROGRAM DEVELOPMENT

EVERYBODY CAN COOK: TECHNIQUES FOR THE HANDICAPPED (Teacher Manual, Student Manual and Student Profiles of Skills)
Author: Henrietta Baron
Date: 1978
Source: Special Child Publications
4535 Union Bay Place N.E.
Seattle, Washington 98105

Lesson plans for teaching the physically and mentally handicapped to prepare low-budget, nutritious meals independently. Illustrations aid those with limited visual or reading ability.

EVERYDAY BUSINESS
Author: Gary D. Lawson
Date: 1970
Source: Gary D. Lawson
9488 Sara Street
Elk Grove, California 95624

Designed to help mildly retarded and some moderately retarded adults' fundamental skills in the areas of banking, budgeting, buying, federal income taxes and insurance.

FUNCTIONAL AIDS FOR THE MULTIPLY HANDICAPPED
Author: Isabel P. Robinault
Date: 1973
Source: Medical Department
Harper & Row, Publishers
Hagerstown, Maryland 21740

A resource book of equipment, materials and techniques for working with individuals who have multiple handicaps. Areas include:

- Transfer, travel and mobility
- Personal care
- Communications and learning
- Recreation

GUIDE TO THE COMMUNITY. (3 volumes)

Date: 1974
Source: Elwyn Educational Materials Center
Elwyn Institute
Elwyn, Pennsylvania 19063

Volume I: Employment, money management, banking, & your paycheck. Volume II: Income tax, life insurance, health insurance, & social security. Volume III: Driving a car, finding a place to live, legal emergencies, community services, medical emergencies.

INDEPENDENT LIVING TEACHING MANUAL (2 volumes)

Author: Robert L. Schalock
Date: 1975
Source: Mid-Nebraska Mental Retardation Services
P.O. Box 1146
Hastings, Nebraska 68901

The two-volume set includes an Independent Living Screening test manual in addition to this teaching manual. The manual contains a sequenced list of target behaviors, which, when remediated, combine to produce functional behaviors. Specific teaching objectives, materials and teaching techniques are presented in reference to each target behavior.

INVENTORY OF HABILITATION PROGRAMS FOR MENTALLY HANDICAPPED ADULTS

Date: 1974
Source: Portland Habilitation Center
3829 S.E. 74th Avenue
Portland, Oregon 97206

A 500+ page comprehensive curriculum training program for teaching moderately and severely retarded adults. The inventory is divided into four habilitation programs: Part I — Social Behaviors; Part II — Practical Living Skills; Part III — Socialization Skills; and Part IV — Job Skills.

LEARNING ABOUT TIME

Authors: Raymond J. Bohn and John D. Wool
Date: 1969
Source: Frank E. Richards Publishing Co.
215 Church Street
Phoenix, New York 13135

Time telling skills are broken down into the following components:

- What is time?
- The clock's face
- A.M. or P.M.
- O'Clock
- Telling time
- The half hour and quarter hour
- Writing time
- Roman numerals
- The calendar
- Writing the date

LEARNING STEPS: A HANDBOOK FOR PERSONS WORKING WITH DEAF-BLIND CHILDREN IN RESIDENTIAL SETTINGS

Date: 1976
Source: Southwestern Region Deaf-Blind Center
721 Capitol Mall
Sacramento, California 95814

An illustrated handbook designed for those working directly with children who are deaf and blind, but the information is equally useful for those working with all severely multihandicapped children regardless of primary handicapping conditions.

MANAGING BEHAVIOR, PARTS 1, 2 and 3

Author: R. Vance Hall
Date: Undated
Source: H & H Enterprises, Inc.
P.O. Box 1070
Lawrence, Kansas 66044

Part 1 — The Measurement of Behavior. Explains types of behavior, how behavior is recorded and analyzed and research designs and their uses.
Part 2 — Behavior Modification: Basic Principles. Explains the theory underlying operant conditioning, how various procedures are applied to human behavior, procedures for decreasing behavior and how naturally available consequences are used to modify a wide range of behavior.
Part 3 — Applications in School and Home. Explains techniques used in modifying human behavior in educational and social settings.

MEALTIMES FOR SEVERELY AND PROFOUNDLY HANDICAPPED PERSONS

Editors: Robert Perske, Andrew Clifton, Barbara M. McLean, and Jean Ishler Stein
Date: 1977
Source: University Park Press
233 East Redwood Street
Baltimore, Maryland 21202

A collection of short articles relating to concepts and attitudes associated with mealtimes. Contains much useful advice and experience on the developmental aspects of eating, skills training, and human interactions.

PICTORIAL SHOPPING AND MEAL PLANNING GUIDE

Date: Undated
Source: Developmental Services, Inc.
Residential Services
P.O. Box 1023
Columbus, Indiana 47201

The non-reader is at a severe loss when he attempts to make out a shopping list or weekly meal plan. This guide was developed to meet the needs of the increasing number of individuals who are living in residential programs. This pictorial shopping guide and meal planner is a vehicle to assist the resident to function better in the community.

PLANNING FOR YOUR OWN APARTMENT

Author: Virginia S. Belina
Date: 1975
Source: Fearon Publishers
Lear-Siegler, Inc.
6 Davis Drive
Belmont, California 94002

A practical guide for preparing students for independent living is divided into the following units:

- Planning to live on your own
- Looking for an apartment
- Planning for furnishing your apartment
- Shopping and buying for your apartment
- Planning budgets and sharing expenses
- Getting things together
- Decorating your apartment
- Sharing responsibilities

PLANNING MEALS AND SHOPPING

Author: Ann A. Weaver
Date: 1970
Source: Fearon Publishers
Lear-Siegler, Inc.
6 Davis Drive
Belmont, California 94002

The components of meal planning and food shopping are broken down into the following steps:

- Choosing the right foods
- Planning nourishing meals
- Planning meals for a week

- Making a shopping list
- Choosing a food store
- Getting the most for your money
- Storing the food you buy
- Getting ready for mealtimes

PRACTICAL GUIDELINES: A MINICOURSE IN PROGRAM DESIGN FOR THE DEVELOPMENTALLY DISABLED
Authors: Herbert R. Padzensky & E. Jane Gibson
Date: 1978
Source: Educational Consultant Enterprises, Inc.
P.O. Box 1471
Greeley, Colorado 80631

Among the topics covered are uses of assessment data, material resources, human resources, learning styles, learning modalities, reinforcers, choosing instructional materials, adapting instructional materials, staffings, and planning guide. This minicourse is an outstanding guide for long-term, short-term and daily planning.

A SPECIAL PICTURE COOKBOOK
Author: Frieda Reed Steed
Date: 1974
Source: H & H Enterprises, Inc.
Box 3342
Lawrence, Kansas 66044

A simple illustrated step-by-step manual, designed to help retarded individuals learn to prepare a few basic food items. The manual is organized as follows: A simple discussion of cleanliness, learning to measure, starting to cook, using the stove, etc. Kitchen vocabulary is taught (using both pictures and words). Simple recipes are broken down into beverages, cakes, cookies and candy, salads and vegetables, main dishes, etc.

TRAINING THE RETARDED AT HOME OR IN SCHOOL
Author: Earl E. Balthazar
Date: 1976
Source: Consulting Psychologists Press, Inc.
577 College Avenue
Palo Alto, California 94306

A manual for parents, home trainers, teachers and others involved in direct care. Focus of the manual is on fundamental self-care skills and basic social coping behaviors. Materials are designed to supplement and reinforce the training the retarded person may be receiving outside the home.

YOU AND YOUR WORLD
Author: Willeta R. Bolinger
Date: 1962
Source: Fearon-Pitman Publishers
Lear-Siegler, Inc.
6 Davis Drive
Belmont, California 94002

Designed to assist the mildly retarded individual in adapting to his/her surroundings. Material includes the following units:

- You
- Your family
- Your neighborhood
- Your school
- Your city
- Your country
- Your state
- Your continent
- Your world

Staff Related:

BASIC COURSE FOR RESIDENTIAL CARE WORKERS
Date: 1977
Source: Group Child Care Consultant Services
School of Social Work
University of North Carolina
Chapel Hill, North Carolina 27514

The course is organized into seven units. Each unit may be used separately or in combination with other units. Each unit has a student manual and a corresponding instructor's manual. Manual I: Developmental planning; Manual II: Developmental needs; Manual III: Separation; Manual IV: The cottage; Manual V: Discipline; Manual VI: The group; Manual VII: The job.

EDUCATION FOR FOSTER FAMILY CARE: MODEL AND METHOD FOR FOSTER PARENTS AND SOCIAL WORKERS
Authors: Helen D. Stone and Jeanne M. Hunzeker
Date: 1974
Source: Child Welfare League
67 Irving Place
New York, New York 10003

Basic material is presented on preservice and inservice educational programming for foster parents and foster family social workers together with a number of models of how these basics can be, and are being, implemented locally.

EVALUATING INDIVIDUALIZED GOAL PLANS: HOW TO CATCH YOUR STAFF DOING SOMETHING RIGHT
Authors: Peter S. Houts and Robert A. Scott
Date: 1975
Source: Department of Behavioral Science
The Pennsylvania State University
College of Medicine
Milton S. Hershey Medical Center
Hershey, Pennsylvania 17033

A "comic book" format is used to teach the elements in planning goals for developmental programs. Models are given for assessment reviews and goal planning.

LIFE PROJECT: GROUP HOME PARENT TRAINING PROGRAM
Author: The Harry A. Waisman Center on Mental Retardation and Human Development
University of Wisconsin
Date: 1976
Source: Stanfield House
P.O. Box 3208
Santa Monica, California 90403

A training program for group home staff. The program consists of eight programmed, self-teaching units covering the following subjects:

- Introduction to mental retardation and community living
- Home management
- Health and hygiene
- Behavior management
- Sexuality
- Recreation and leisure time
- Community resources and relations
- Social competency

OPERATING MANUAL FOR RESIDENTIAL SERVICES PERSONNEL
Date: 1974
Source: Nisonger Center for Mental Retardation & Developmental Disabilities
1580 Cannon Drive
Columbus, Ohio 43210

The first part of this manual focuses on effective administration in operating a group home. Part two gives basic information and programming for residential services personnel, followed by emergency information and procedures. Part three gives sample forms.

THE RESIDENTIAL CHILD CARE WORKER
Date: 1978
Source: Group Child Care Consultant Services
University of North Carolina
300 Battle Hall 056-A
Chapel Hill, North Carolina 27514

A comprehensive course of study for adults who work with children in residential facilities. It develops skills and knowledge in seven fundamental subjects: developmental planning; developmental needs; separation; the cottage; discipline; the group; and the job.

RESIDENT MANAGER EDUCATION: A CURRICULUM MODEL FOR EDUCATING FOSTER PARENTS AND GROUP HOME PERSONNEL
Date: 1977
Source: Macomb-Oakland Regional Center
16200 Nineteen Mile Road
Mt. Clemens, Michigan 48043

The book shares thoughts on the subject of resident manager education and training. This volume is not intended to answer all questions about resident manager education but does attempt to share experiences worth considerable attention.

Language:

BALL-STICK-BIRD READING METHOD
Author: Renee Fuller
Date: 1974
Source: Renee Fuller
P.O. Box 592
Stony Brook, New York 11790

A simplified method of teaching reading using illustrations and high interest science fiction material. The method is designed for use with substantially retarded individuals. The method has been reported successful in teaching severely retarded young adults to read.

BASIC SPEECH IMPROVEMENT MANUAL
Date: 1976
Source: Elwyn Educational Materials Center
Elwyn Institute
Elwyn, Pennsylvania 19063

A guide for the teacher of the developmentally disabled child — children with poor academic ability due to mental retardation, brain injury or emotional disability. Designed to help teachers identify and develop simple speech and articulation patterns.

COMMUNICATION RESOURCES FOR THE DEVELOPMENTALLY DISABLED: A GUIDE FOR PARENTS, PARAPROFESSIONALS AND PROFESSIONALS
Authors: Kalisankar Mallik, Elaine Shaver, Elizabeth High, & James Mueller
Date: 1977
Source: The Job Development Laboratory
George Washington University
Rehabilitation Medicine
2300 Eye Street, N.W. Room 420
Washington, D.C. 20037

A guide of resources related to language and communication. The 255-page volume is divided into four sections containing information in the areas of books, film, articles, devices, catalogs and source books, describing ways to improve communication among developmentally disabled persons.

THE ENVIRONMENTAL LANGUAGE INTERVENTION PROGRAM (ELI)
Authors: James D. MacDonald & DeAnna S. Horstmeirer
Date: Undated
Source: Charles E. Merrill Publishing Company
Department CDM
1300 Alum Creek Drive
Columbus, Ohio 43216

The ELI was developed at the Nisonger Center at Ohio State University and has proven a successful training method for children with Down's syndrome, mental retardation, cerebral palsy, brain damage, learning disabilities, neurological impairment, deafness and blindness. This series of training programs establishes prelanguage skills and initial verbal communication in those who have yet to develop socially useful language.

FORM-A-PHRASE SYSTEM
Developer: SicTronics, Inc.
Date: Undated
Source: SicTronics, Inc.
523 South Clewell Street
P.O. Box 5344
Bethlehem, Pennsylvania 18015

An electronic device to assist non-verbal individuals in communicating through the use of 128 words and phrases, plus an electronic voice which actually speaks the word involved.

HANDIVOICE
Developer: Phonic Mirror
Date: Undated
Source: HC Electronics, Inc.
250 Camino Alto
Mill Valley, California 94941

A hand-held electronic voice synthesizer which enables the non-verbal individual to create a virtually unlimited English language vocabulary by combining basic component sounds.

LANGUAGE DEVELOPMENT TRAINING PROGRAM FOR MULTIHANDICAPPED
Developers: ZYGO Industries
Date: 1976
Source: ZYGO Industries, Inc.
P.O. Box 1008
Portland, Oregon 97207

This program is to be used with the Model 16 ZYGO Communication Board which is an electronic device with 16 successively lighted display panels. Using a suitable switch, the user determines which panel stays lighted, thereby communicating the message on that panel. The materials provided include an instructor training manual, an exercise book, message display overlay panels and forms for assessing initial levels and progress. The training program is designed to be administered by non-professionals.

NON-SLIP (Film)
Producers: Kansas Center for Mental Retardation & Human Development
Date: 1976
Source: The University of Kansas
Kansas University Affiliated Facility
223 Haworth
Lawrence, Kansas 66045

Non-SLIP (Non-Speech Language Initiation Program) is a 25-minute, 16mm, color film demonstrating in general form the procedures used in the Non-SLIP training and gives some background in the area of symbolic language research.

READING FOUNDATIONS PROGRAM (4 Volumes)
Date: 1972, 1973, 1974
Source: Elwyn Educational Materials Center
Elwyn Institute
Elwyn, Pennsylvania 29063

A four-volume series providing programs for developing language and reading readiness skills plus supplementary workbooks to reinforce beginning reading.

SAFETY FOR ME
Authors: Mary Baird & Norman Levine
Date: 1966
Source: Stanwix House, Inc.
3020 Chartiers Avenue
Pittsburgh, Pennsylvania 15204

A workbook designed to assist retarded individuals in developing a sight vocabulary of words that may be important in protecting oneself from danger.

TUTOR'S SAMPLER
Authors: Lillie Pope, Deborah Edel, & Abraham Hakley
Date: 1973
Source: Book-Lab, Inc.
1449 37th Street
Brooklyn, New York 11218

Designed for use with students who have reading problems and perceptual problems. Instructional materials are individualized with emphasis on techniques to supplement reading instruction such as eye-hand coordination, listening skills, dealing with similarities and differences, and directionality. Suitable for mildly, moderately and some severely retarded students.

YOUR CHILD CAN TALK, TOO
Date: 1972
Source: Elwyn Educational Materials Center
Elwyn Institute
Elwyn, Pennsylvania 19063

Provides individual step-by-step program for teaching language to non-verbal, preschool age, handicapped children. Primarily for parents and teachers. Presents operant conditioning approaches to teaching receptive, expressive and inner language.

Dental Care:

DENTAL CARE OF HANDICAPPED CHILDREN
Author: Joan Weyman
Date: 1971
Source: Williams & Wilkins
428 East Preston Street
Baltimore, Maryland 21202

DENTAL CARE FOR ADULT PATIENTS WITH CEREBRAL PALSY
Authors: Solomon N. Rosenstein & Marvin B. King
Date: 1973
Source: United Cerebral Palsy of New York City, Inc.
339 East 44th Street
New York, New York 10017

This booklet presents some basic information to promote understanding of cerebral palsy and the patients with that condition.

DENTISTRY FOR THE HANDICAPPED PATIENT
Editor: Arthur J. Nowak
Date: 1976
Source: C.V. Mosby Co.
11830 Westline Industrial Drive
St. Louis, Missouri 63141

A new textbook for the dental profession, primarily.

HOME DENTAL CARE FOR THE HANDICAPPED CHILD
Author: Linda S. Schey
Date: 1976
Source: The New England Developmental Disabilities Communication Center
200 Trapelo Road
Waltham, Massachusetts 02154

The suggestions and adaptive dental techniques recommended in this manual are designed to stimulate interest, skill development and teamwork while promoting good oral health at home.

TOOTHBRUSHING AND FLOSSING: A MANUAL OF HOME DENTAL CARE FOR PERSONS WHO ARE HANDICAPPED
Author: Paul Casamassimo

Date: 1977
Source: The National Easter Seal Society for Crippled Children and Adults
2023 West Ogden Avenue
Chicago, Illinois 60612

This booklet is aimed at prevention of the major mouth diseases through measures that can be taken in the home to keep both teeth and gums free of plaque.

Behavior Modification:

Baldwin, V.L., Fredericks, H.D., & Brodsky, G. **Isn't It Time He Outgrew This: or, A Training Program for Parents of Retarded Children.** Springfield, Illinois: Charles C. Thomas, Publisher, 1973.

Bannatyne, A. & Bannatyne, **How Your Children Can Learn to Live a Rewarding Life.** Springfield, Illinois: Charles C. Thomas, Publisher, 1973.

Becker, W.C. **Parents Are Teachers.** Champaign, Illinois: Research Press Company, 1971.

Berkowitz, B.P. & Grazlano, A.N. Training parents as behavior therapists: A review. **Behavior Research & Therapy**, Vol. 30, pp. 297-317, 1972.

Brown, D.G. **Behavior Modification in Child, School, and Family Mental Health: An Annotated Bibliography.** Champaign, Illinois: Research Press Company, 1972.

Favell, J.E. **The Power of Positive Reinforcement: A Handbook of Behavior Modification.** Springfield, Illinois: Charles C. Thomas, Publisher, 1977.

Gardner, W.I. **Behavior Modification in Mental Retardation.** Chicago: Aldine-Atherton, Inc., 1971.

Kunzelmann, H.P. (ed.). **Precision Teaching.** Seattle, Washington: Special Child Publications, Inc., 1970.

Lovaas, O.I. & Bucher, B.D. (eds.). **Perspectives in Behavior Modification with Deviant Children.** Englewood Cliffs, New Jersey: Prentice-Hall, Inc., 1974.

Padzensky, H.R. & Gibson, J. **Goalguide: A Minicourse in Writing Goals and Behavioral Objectives for Special Education.** Belmont, California. Fearon Publishers, 1976.

Pascal, C.E. Using principles of behavior modification to teach behavior modification. **Exceptional Children**, pp. 426-430, May 1976.

Patterson, G.R. **Families: Applications of Social Learning to Family Life.** Champaign, Illinois: Research Press Company, 1971.

Patterson, G.R. Behavioral intervention procedures in the classroom and in the home. In: A.E. Bergin and S.L. Garfield (eds.). **Handbook of Psychotherapy and Behavior Change.** New York: Wiley, pp. 751-775, 1969.

Patterson, G.R. & Gullion, M.E. **Living with Children: New Methods for Parents and Teachers.** Champaign, Illinois: Research Press Company, 1976 (Revised Edition).

Reynolds, G.S. **A Primer of Operant Conditioning.** Glenview, Illinois: Scott, Foresman and Company, 1968.

Roos, P. Human rights and behavior modification. **Mental Retardation**, pp. 3-6, June 1974.

Skinner, B.F. The steep and thorny way to a science of behavior. **American Psychologist**, pp. 42-49, January 1975.

Tawney, J.W., Middleton, D.M., & Cegelka, P.T. Behavior modification is NOT . . . **Teaching Exceptional Children**, pp. 82-89, Winter 1973.

Tharp, R.G. & Wetzel, R.J. **Behavior Modification in the Natural Environment.** New York: Academic Press, Inc., 1969.